

Learning to See Invisible Children

Inclusion of Children with
Disabilities in Central Asia



EDITED BY
MARTYN ROUSE AND KATE LAPHAM

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**Inclusion of Children with Disabilities
in Central Asia**

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Martyn Rouse and Kate Lapham

Open Society Foundations

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We dedicate this volume to two dear friends and colleagues who championed the cause of human rights and inclusion throughout their lives and passed away, much too early, during the writing of this book.

In Memoriam

Tom Alexander (1940–2012)

Anna Alexandrova (1976–2011)

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Introduction

Martyn Rouse and Kate Lapham

Rationale for the Book

In spite of worldwide efforts to achieve Education for All (UNESCO 1990, 2001) and attempts to develop inclusive education, there is very little literature reporting on local and national initiatives to extend educational access to all children in the countries of Central Asia. International agencies including UNICEF (2005, 2007) and UNESCO (2010) have published reviews of education and provision for vulnerable and disabled children in many regions of the world, including Central Asia (OECD 2009; UNICEF 2010, 2012). However, there is little research-based literature that reports on local or national initiatives designed to improve services and provision for children with disabilities in the region. Local and international non-governmental organizations (NGOs) have been involved in the development of small-scale initiatives since the breakup of the Soviet Union more than 20 years ago, but other than the evaluation reports on these projects, not all of which are in the public domain, little has been published that might provide the evidential foundation for further developments in education for children with disabilities in the region and elsewhere.

In this context, the Education Support Program of the Open Society Foundation has supported a variety of organizations providing educational services to disabled children and their parents as an important way of filling gaps in the current system and demonstrating local services with the potential for replication. As education systems across the region demonstrate increasing interest in inclusive education, it is even more important to understand the genesis, successes, and challenges of these local

models and to explore how they might contribute to system-level reform (Stake 2005).

In addition to driving education policy reform in the region, the Open Society Foundation has also identified a gap in academic research covering inclusion of children with disabilities in Central Asia. In the hope of contributing to research in the field of inclusive education, in 2011 the Open Society Foundation began expanding and updating a series of case studies on local models of inclusion in Central Asia with the goal of understanding the barriers and opportunities for groups of ordinary citizens who come together into associations, foundations, and other types of NGOs to serve the needs of children with disabilities. In an environment that still strongly favors segregation and institutionalization, a growing number of parents and professionals are acting on their own initiative to increase the social and educational inclusion of children with disabilities. In many cases they are quite revolutionary in their approach to building and gaining access to services by fundamentally redefining the meaning of education and every child's right to participate. What has motivated them? How have they found ways forward in very tight funding environments to advance an issue often characterized as a luxury or low priority? How do they see the future of their work?

Overview of the Book

The Open Society Foundation identified six cases in Kazakhstan, Kyrgyzstan, and Tajikistan that address a significant aspect or specific phenomenon in the local context of inclusive education or social inclusion. The cases raise a number of questions relating to the purpose and nature of schooling, about who should have access to schools and how such access might be negotiated. These cases also ask questions about the respective roles of policy, parents, civic society, advocacy groups, professionals, NGOs, and government agencies. It considers how notions of disability are constructed in the region. In particular it looks at some of the ways in which the Soviet legacy of "defectology" still informs policy and practice today. Specifically, the questions include:

- To what extent do education policies and practices include or further marginalize the most vulnerable?
- How are services structured to account for the needs of different groups?

- Are government programs using education as an equalizing force, particularly in the early years, or are educational policies and practices designed to preserve the status quo, or create new elite groups?
- Does the broader community of teachers, parents, and children have meaningful opportunities to participate in the conception, design, delivery, and monitoring of education?
- How is disability defined in the region, and to what extent are these notions of disability consistent with social and interactive models of disability in other parts of the world?
- What are the implications for the reform of teacher preparation and professional development for those who work to support children, young people, and their families?

By asking these questions, we can examine whether policies are inclusive in their design and implementation. In turn, by observing inclusion at the community, school, and classroom level, we can see the realities of how policies interact with practice and think about the next steps in building a more inclusive future.

These questions are addressed in the context of a Soviet legacy, which was clear about how best to deal with disability and about professional responsibilities, boundaries, and identities, especially in the field of disability. Furthermore, the three countries are in transition, not only politically, economically, and socially, but also in the ways in which education is being conceptualized and reformed.

The six case studies provide snapshots of the classrooms and communities as they exist now. They have not been constructed specifically to answer the questions outlined above, but the messages that emerge from the case studies provide answers to many of the questions. The case studies document both progress and barriers on the road to inclusive education. They paint a picture of the evolving understanding of disability, education, and society in Central Asia that is similar to the path that many Western countries have already walked, but is also specific to the cultures and history of the region.

The case studies report on initiatives involving the establishment of parent advocacy groups and the development of inclusive schools, often in a hostile policy environment. The major themes that emerge from this work are the ways in which parents and civil society are leading the conversation about inclusion, the importance of making allies within the government systems, and the bravery of individual people who, without fan-

fare, challenge stereotypes every day. Details of the context for each of the case studies are provided, along with a brief overview of how the case studies were conducted. Implications for the development of future practice are explored.

But before details of the case studies are presented, it is important to locate the developments in Central Asia within worldwide efforts to educate all children as part of the international commitment to achieving Education for All (EFA).

The Broader Context

Education for All?

Early efforts to achieve EFA, a major international initiative launched in 1990 at the World Conference on Education for All (EFA) in Jomtien, Thailand (UNESCO 1990), did not specifically mention the education of children and young people with disabilities. However, the link between inclusive education and EFA has subsequently been stressed (UNESCO 2005). Because children with disabilities are the most likely to be excluded from education in many parts of the world, EFA cannot be achieved without inclusive education. Many commentators (Florian 2007, 2011; Miles and Singal 2009; Opertti and Brady 2011; Peters 2004) and international agencies (UNICEF 2012; UNESCO 2005, 2008) have recognized the links between inclusive education and the aspirations of the EFA movement. This is particularly relevant in Central Asia and other countries of the former Soviet Union, because the legislative framework in this part of the world specifically excluded or restricted access to mainstream education for children with disabilities, even when education was supposed to be compulsory and free (UNICEF 2005). The legacy of these exclusionary tendencies is still apparent today, not least in the medical approaches to the assessment and “treatment” of people with disabilities in segregated boarding schools based on type of disability. Efforts to achieve inclusive education in the region have to be understood in this historical context, where institutional and professional inertia means that many policies and practices of the past are carried into the present.

In many parts of the world and in most international declarations on the topic, the concept of inclusive education has been broadened beyond children with disabilities to encompass other vulnerable groups such as Roma children, refugee children, street children, child workers, children living in

remote rural areas, child soldiers, children living in extreme poverty, and children from indigenous and nomadic groups. Indeed, many children who belong to such vulnerable groups are often described as having special educational needs, because it is a convenient way to provide services to them and/or to justify their segregation. In attempting to develop inclusive education, the concern is for anyone who might be excluded from, or have limited access to, schooling with their peers within a country (UNESCO 2010). The rights of children with disabilities to have access to, and to participate in, a country's general education system have become firmly established as part of the EFA and other human-rights agendas such as the Convention on the Rights of the Child (United Nations 1990) and the Convention on the Rights of Persons with Disabilities (United Nations 2006).

Attempts to achieve EFA often focus on reducing barriers to participation for marginalized individuals and groups, and these attempts will vary according to local circumstances. Thus inclusive education will be defined and enacted in different ways in different areas, depending on the purpose and nature of schooling, how it is organized, who has access to it, and who has been denied access in the past (Ainscow and Miles 2008). Nevertheless, in spite of international pronouncements and promises, progress in achieving EFA has been slow. Many of the estimated 60 million children worldwide who do not currently have access to schooling are disabled (UNESCO 2010). As part of the efforts to improve the rate of progress and government accountability in meeting EFA goals, the annual Global Monitoring Report (GMR), published by the United Nations Educational, Scientific and Cultural Organization (UNESCO), has been established as a reference work for tracking the progress towards EFA. A recent GMR (UNESCO 2010) specifically focused on marginalized children. The GMR includes the latest available statistics in nine regions of the world, including Central Asia. In this way, governments can be held to account for their achievements in educating all children.

The Region

Central Asia consists of five former Soviet republics: Kazakhstan, Kyrgyzstan, Tajikistan, Turkmenistan, and Uzbekistan. It is a vast region that stretches from the Caspian Sea in the west to China in the east, and from Russia in the north to Afghanistan in the south. Much of the region consists of steppes bounded to the south by mountain ranges. The climate is continental, with large seasonal variations. Historically and culturally, the region is closely associated with its nomadic traditions and with trade

along the Silk Road between Europe and Asia. As a result it has long been at the crossroads for goods, migration, and the exchange of ideas, languages, and religions. Patterns of educational provision in the region are still influenced by its Soviet legacy, but in spite of limited resources, reforms are occurring in several countries.

During the past 20 years or so, the region has experienced significant transition in economic, social, political, and educational spheres. Not all areas or people have benefited from these reforms, and many parts of the region are poor, especially rural areas, while other areas are more prosperous. Civil wars after the breakup of the Soviet Union affected the region and resulted in the large-scale relocation of certain ethnic groups, creating further challenges to the provision of schooling.

The transition to a market economy in the region has not been easy. Many jobs were lost in the public sector, and traditional manufacturing industries were closed. In addition to the forced movement of populations mentioned above, economic migration is a significant factor in many areas, as people leave the region to seek employment elsewhere, especially in Russia. This large-scale movement of (mainly young men) has altered the social fabric of many communities and families. In contrast, some areas have seen new patterns of employment emerge, and they have benefited from revenues from natural resources. In particular, Kazakhstan has seen its gross domestic product rise as a result of oil production.

The Case-Study Countries

Kazakhstan

Kazakhstan is a vast country, the size of Western Europe, and is the ninth biggest country in the world by land area. The population of Kazakhstan is around 15 million; just over half are Kazakh, a third are Russian, and other ethnic groups make up the remainder. Forty-seven percent of the population are Muslim, while 44 percent are Russian Orthodox. The official state language is Kazakh, spoken by over half of the population. Russian is spoken by two-thirds of the population and is also recognized as an official language. Schools offer classes in both languages, and both serve as languages of instruction (OECD 2009). Increasingly, English is being taught in schools.

Kazakhstan is in a stronger economic position than other countries in the region. Although the early years of independence were marked by a

severe economic depression and cuts to education, current and future revenues from natural resources make greater investment in education possible. The president has made a clear commitment to transform the education system to produce graduates who can compete on a global level. Education is seen as the key to ensuring that the country can capitalize on its natural wealth and assume a new global leadership role. According to the OECD (2009), every child in Kazakhstan has the right to education and is guaranteed a free primary, general secondary, and basic vocational education and free secondary and higher professional education on a competitive basis, regardless of origin, ethnicity, social and property status, gender, language, education, religious affiliation, place of residence, health status, or other circumstances.

As part of the efforts to improve education in the country, a number of radical reforms have been introduced, some bearing the president's name, including Nazarbayev University and Nazarbayev Intellectual Schools (NIS). The plan is for 20 highly selective schools to be established to prepare students to enter the university. These schools have been recruiting staff internationally and plan to teach the curriculum in three languages: Kazakh, Russian, and English. At the same time, in association with NIS and in partnership with a number of international universities, the national Center of Excellence is engaged in a large-scale initiative involving the retraining of tens of thousands of teachers across the country. Although the teacher retraining program stresses the importance of formative assessment, creative thinking, and problem solving, it also stresses planning for the "gifted and talented," rather than planning for diversity and individual differences. Currently, issues relating to children with disabilities and inclusion are not part of the retraining program.

At this stage it is unclear whether these reforms will create greater capacity within the teaching workforce of schools. Since the NIS network is managed by the Presidential Administration rather than the Ministry of Education and Science, these reforms could lead to a two-tier teaching profession and system of schooling consisting of a few well-resourced schools staffed by highly trained teachers who are paid more than other teachers.

There have also been statements about the need to improve human rights and the recognition of the need to address the current inadequate system of providing quality education for children with disabilities. As signaled by the ratification of the UN Convention on the Rights of Persons with Disabilities in 2008, there has been interest in adopting the worldwide trend of including children with disabilities in the regular

schools, although some of the current high-profile education reform efforts mentioned above do not specifically address inclusion and the education of children with disabilities. According to the OECD (2009: 52),

despite the law and derived policies promoting the education of children with disabilities, as yet they are not included in the broader discussions of educational reform. It is clear that this omission is incompatible with the concept of inclusive education and... with the commitments Kazakhstan has made to the international community and even in its own constitution.

Indeed, the government's commitment to make 70 percent of schools into inclusive schools by 2020 (State Program for the Development of Education in the Republic of Kazakhstan: Astana, 2010) seems an ambitious target.

Kyrgyzstan

The Kyrgyz Republic has just over 5 million inhabitants, the majority of whom live in rural areas. About two-thirds of the population are Kyrgyz; Uzbeks and Russians are the two other main ethnic groups. The national language is Kyrgyz, and many people also speak Russian. With the breakup of the Soviet Union, the Kyrgyz Republic suffered a severe economic recession. It has since stabilized, but according to the OECD (2009), unemployment is around 20 percent. It does not have the benefit of Kazakhstan's natural resources, although it does have hydroelectric power, a small mining industry, and an important agricultural sector.

The educational policies in the Kyrgyz Republic promote an inclusive education system consistent with the goals of EFA. It aspires to high levels of enrollment, regular attendance, and low levels of repetition and dropout rates. The concept of inclusive education is not limited to children with disabilities, but expresses the view that *no child* should be excluded from education, and that *each child* should be able to participate actively in all domains of society (OECD 2009). The reality is that poorly resourced schools struggle to meet the learning needs of all children. Teachers are poorly paid, and teacher recruitment and retention is a problem, especially in rural areas, leading to teacher shortages (Steiner-Khamisi 2011). Less than 80 percent of teachers in primary and secondary schools are qualified, in spite of the fact that only half the graduates of the state pedagogic universities choose to work as teachers (National Statistics Committee 2008). Even the qualified teachers may lack the necessary skills for working in inclusive ways because of the weakness of teacher

training. Not only do teachers lack appropriate teaching skills and knowledge, but there is also a lack of appropriate materials and resources. Thus they are unprepared to deal with a wider range of educational needs in their classrooms, to adapt their pedagogy, and to meet the requirements of inclusive education.

Tajikistan

Tajikistan is a small landlocked country situated in the southeastern part of Central Asia. It has borders with Kyrgyzstan to the north, Afghanistan to the south, Uzbekistan to the west, and China to the east. More than 90 percent of the country is mountainous, and around three-quarters of the population live in rural areas near river valleys. It has a population of around 7 million and is currently experiencing rapid population growth. The majority population is Tajik, with Uzbeks (15.3 percent) forming the largest ethnic minority. An estimated 90 percent of the population is Muslim. Tajik (a variety of Persian) is the official state language, with Russian being used for interethnic communication. Tajikistan declared independence from the Soviet Union in 1991, but civil war soon followed, lasting until a cease-fire in 1997. The literacy rate in Tajikistan is estimated at 99.5 percent, but these figures are not consistent with the high dropout rate from primary education, which is estimated at more than 7 percent (UNICEF 2006).

The Law on Social Protection of the Disabled in the Republic of Tajikistan (Law 675, 2010) defines a “disabled person” as a person “who as a result of unfitness of health with reduction of the functions of performance of tasks of the body due to sickness, injuries, physical and mental disability which causes barriers to life activities and need to social protection.” One of the main concerns of the Law on Social Protection is to provide the basis for the participation of the disabled in the economic and political life of the country. This law guarantees people with disabilities “access and equal rights... at the level of other citizens to health, education, recreation, and tourism.” Nevertheless, at this time Tajikistan has no specific law on special or inclusive education, which effectively leaves the children with special educational needs out of policies aimed at integrating people with disabilities into society (OECD 2009). The government of Tajikistan has taken steps to improve this situation by developing a Concept on Inclusive Education in 2011 to be included in the National Education Development Strategy. Although it does not have the force of law and does not aim for the type of full education inclusion described in Article

24 of the UN Convention on the Rights of Persons with Disabilities, it is a positive step.

Although there are some university teachers, officials, and NGOs who understand and promote the concept of inclusive education, the general public, including many educational professionals, has little or no understanding of the concept of inclusive education or how to develop it (OECD 2009).

Education in the Region: The Soviet Legacy

The countries of Central Asia share a Soviet legacy, which still influences the ways in which education and other human services are conceptualized and organized today. Historically, the Soviet Union had high rates of enrollment in schooling and high levels of literacy and attainment. For some children, high standards were achieved, and for some professionals and parents, there is a sense of nostalgia for the certainties of the past. Since the fall of the Soviet Union, the countries of Central Asia have been grappling with education reform. In most cases, the goal of reform has been sustaining or resurrecting the Soviet system of education or adopting measures associated with higher achievement in the West.

During the Soviet period and beyond, schooling was not equally available to all children. This was especially true for provision for children and young people with disabilities. Inclusion of such children has traditionally been viewed outside these frameworks of reform because the traditional approach—known as defectology—frames disability as a diagnosis for treatment and rehabilitation rather than just one aspect of a whole child requiring adaptations in the learning environment (Daniels 2005). Thus inclusion becomes an act of pity or charity for children who are viewed as not having the potential to succeed in schools as they currently exist. This view is detrimental not only to children with disabilities, but to all children, because it perpetuates a rigid, standardized model of education based on the outdated idea of a fixed or finite capacity to learn rather than fostering children's individual talents and infinite potential (UNICEF 2007).

A legacy of the Soviet period is that children who were assessed and classified by psychological-medical-pedagogical commissions (PMPCs) as having disabilities were likely to have been placed in residential institutions, often far from their families and other forms of natural support, where they would have been “treated” by specialists trained as “defectologists.”

Defectology has its origins in early Soviet attempts to understand and treat handicap. It has a long history and continues to be influential in the

countries of the former Soviet Union, including Central Asia (Daniels 2005). The founder of Soviet psychology, Lev Vygotsky, is considered the “father” of defectology, which emerged from debates in the 1920s and 1930s about the nature of handicap (Florian and Becirevic 2011) and how it should be dealt with. Over time, defectology, as a field of study and a way of organizing practice and provision, changed from an approach that explained disability as a bio-psycho-social phenomenon to a series of practices that emphasized deficits. Most Western commentators are critical of defectology and see it as a barrier to the development of inclusion because it focuses on deficits that are thought best dealt with in segregated provision (Des Power and Blatch 2004). Nevertheless, some professionals who have been trained as defectologists are at the heart of the inclusion movement in the former Soviet Union and are keen to build on the positive elements of the tradition (Florian and Becirevic 2011). Indeed, some of the supportive professionals who feature in the case studies were trained as defectologists.

Throughout the region this traditional “medical model” of disability still largely determines legislation, policies, and provision for people with disabilities. It affects the assessment, classification, and categorization of children with disabilities, as well as determining how and where they should be educated. Children with disabilities may not be seen as the responsibility of the Ministry of Education but are instead placed under the “protection” of the Ministry of Health or the Ministry of Labor and Social Justice. Where available, professional help and provision may still be focused on the *disability* and on “fixing,” “rehabilitating,” or “correcting” it, that is, on making the child “normal,” rather than on working with the child’s functional disorder by helping him or her to adapt to the environment or (better) by adapting the environment so that it becomes accessible to children with disabilities (OECD 2009).

Historically in the former Soviet Union, institution-based special education was favored over community-based inclusive education (UNICEF 2012), and these patterns of provision continue today. In urban areas there may be some special day schools, which permit children with disabilities to live at home. Few children with disabilities attend regular schools, although there are some special classes in mainstream schools. In some cases children with disabilities are educated at home, where home tuition or other forms of support may (or may not) be available. In practice, this option provides little instructional contact between child and teacher and no social contact with other children outside the family. In some rural areas, children with disabilities may be hidden at home because of the

shame and stigma associated with disability. Parents see little point in registering their children when the costs of acknowledging their child has a disability outweigh any potential benefits.

The consequences of the negative beliefs and segregating approaches are wider than education. They also affect social, economic, and community life, resulting in negative attitudes, inaccessible infrastructure, shame and stigma, underemployment, and the isolation of disabled people in special institutions. It was, and continues to be, a system that believes that the separation of children with disabilities is in the best interests of such children, their families, mainstream schools, and broader society. Such beliefs were prevalent in the past and are still apparent today in many areas.

By changing the framework of disability from defectology to inclusion, it is easy to see inclusive education reform as a moral imperative, as exclusion of children with disabilities and learning difficulties from education becomes:

- a human-rights issue, because all children have the right to education, as guaranteed in the Convention on the Rights of the Child and Article 24 of the Convention on the Rights of Persons with Disabilities
- a social-justice issue, because even when children with disabilities attend specialized schools, their segregation from the rest of their peers denies them the opportunity to be active participants in society and to realize their full potential socially and intellectually
- an economic-development issue, because exclusion from education denies children an opportunity to grow into productive members of society and thus denies society the talent and capacity they represent.

But further barriers to inclusion are to be found in mainstream schools, and many claim they are not ready for inclusion. Schools are often physically inaccessible because of steps and stairs. Ramps and elevators are rare. Classrooms may lack sufficient space; they may have narrow doors, poor acoustics, and inadequate heat and lighting. Some schools do not have indoor sanitation and accessible toilets. In addition, it is typical in the region for schools to have little flexibility with the curriculum or pedagogy. Children may be expected to keep pace in lessons that are often very didactic. Despite the substantial investments of international donors and successful pilots, few teachers have been trained in child-centered

pedagogy, activity-based teaching, and collaborative learning. At best, the development of inclusive pedagogies is at an early stage. It is not surprising that the case studies outline the reluctance of some mainstream schools to accept children with disabilities.

Teacher supply and quality is a major challenge in the region. This problem is partly associated with the separation of the training of defectologists from teachers. Many pedagogical universities do not prepare teachers to work in schools that are being asked to become more inclusive, and most departments of defectology are still preparing professionals to work in separate institutional settings. Thus, as the OECD (2009) points out, teachers are not prepared to implement inclusive education, nor are specialists prepared to act as resource persons in preparing students for transition from special schools to regular schools, in supporting teachers from regular schools in their daily tasks, and in involving parents to be part of the education process of their child (OECD 2009). Pre- and in-service training courses do not empower teachers sufficiently to implement the new education objectives introduced by the various reforms of recent years, or to cope with a greater diversity of learners in the classroom.

In some countries there are ongoing attempts to reform the state pedagogical universities, and in Kazakhstan a large-scale professional development program involving tens of thousands of teachers was recently launched. Given that inclusive schools are built one classroom at a time and that quality teachers are crucial to this process, it will be interesting to see whether these initiatives lead to better teaching and learning and ultimately to greater inclusion.

In spite of the challenges outlined above, things are changing. This book presents a series of case studies outlining small-scale initiatives that demonstrate that the first steps to inclusion can be taken when parents, professionals, and policy-makers work together to create a better future for children with disabilities.

The Case Studies

Creating the Research Teams

It is in the context of the historical and educational challenges outlined above that the case studies presented in this volume were conducted. The studies describe and analyze two cases from each of the three countries.

As mentioned earlier, very few accounts of similar initiatives in the region are available. Some have suggested the reason might be that local researchers did not have the necessary qualitative research experience, nor did they have the skills to write in a language that would lead to publication. Often the people who undertook the evaluations of the initiatives were too close to them to present an authoritative account of their difficulties as well as successes. However, when external researchers were used, they may have missed crucial local and contextual knowledge, thus making underinformed judgments based on standards and approaches that they would have expected to see in other places.

To avoid these difficulties, an innovative approach to the design, construction, and writing of the cases was adopted. Six external (international) researchers who had skills and experience in the relevant research methods, as well as the local language skills, worked closely with the local researchers who had deep knowledge of the specific cases. The six research teams were brought together with other internal and external members of the project for a four-day workshop in Istanbul, Turkey, in August 2011. The workshop addressed key elements of the research process, including developing a shared understanding of the task, identifying key research questions, producing a research design, and developing data collection techniques and research instruments. Issues relating to ethical concerns, access, and anonymity were also considered. Although the Open Society Foundation funded some of the initiatives, the purpose of the case studies was not to conduct a program evaluation but rather to produce a series of illustrative case studies that would convey a candid account of the richness, complexity, and messy nature of such development work, while at the same time being as methodologically robust as possible.

The external researchers spent around two weeks in country at the case venues working with their local colleagues on data collection and other research tasks. Each case uses qualitative research methods to answer research questions developed by the teams. Data sources for each case include semi-structured interviews with key informants; reviewing relevant policy and project documents; and carrying out observations during site visits of schools, classrooms, or centers for children with disabilities. The teams analyzed these data and worked together on writing the reports. The cases presented in this volume are the result of this process.

Emerging Themes

A number of common themes emerge. One of the most important is “working together,” how parents support parents, and how parents and professionals work together. The importance of mutual support among parents to take the first step in advocating for their children emerges as a theme in the cases by Markova and Sultanalieva and by Kodirov and Whitsel. Groups of parents in Kazakhstan and Tajikistan first came together informally or as a result of services or education programs offered by other agencies.

In the case by Markova and Sultanalieva, the founders of Ashyk Alem, an association of parents of children with autism, met during parent education classes provided by the SATR (Social Adaptation and Professional Rehabilitation) Center in Almaty, Kazakhstan. In Kardirov and Whitsel’s case, the Association of Parents of Disabled Children (APDC) in Tajikistan started as a single initiative housed in the Psychological-Medical-Pedagogical Commission in Dushanbe, where parents seek referrals to health and education services for children with disabilities. Following the support and encouragement of progressive staff within state agencies in these two cases, both organizations outgrew the affiliation. In both cases, their relationships with the state agencies that helped to create them are friendly, but the scope of their activities has grown well beyond the initial vision of the professionals who saw a need for mutual support among parents.

The parent organizations described in these cases started in state agencies and then became increasingly separate from them as they grew beyond support and service provision to become movements advocating for children’s rights. Ashyk Alem is now working to unite parent groups across the region through the Central Asia Autism Network. The APDC is now an independent network of eleven associations (with plans at the time of writing to engage nine new groups) across Tajikistan that offers physical and occupational therapy, school preparation, and information about children with disabilities. In addition, it provides training and information for parents on the law and children’s rights. It also rallies around families denied access to services or community participation as a result of disability. Parents of children without disabilities do not always welcome inclusive education, worrying that their children will receive less attention from teachers. Parents and professionals who can speak about their experiences with inclusion are vital to this process.

The story of Firuza, the parent of a child with a disability presented by Gatling and Juraeva, is not only moving but also instructive. It demon-

strates the tremendous power of a mother willing to challenge social conventions so that her son could go to school with his peers in Tajikistan. However, it also calls attention to another theme emerging from these cases: the valid concerns and questions that school directors and teachers ask about implementing inclusive education policies. School buildings across the region are inaccessible to many with impaired mobility. The typical school design that remains from Soviet times is two floors without elevators or ramps. The school day, particularly for secondary-school students, is structured around children moving from classroom to classroom at 40-minute intervals. Many schools lack indoor toilets, and the outdoor latrines are not accessible to people with physical disabilities.

These are all problems with solutions. School buildings can be retrofitted with ramps. School directors can reorganize the school day so that teachers move between classrooms to accommodate students who find this difficult. Designs for accessible latrines exist and have been used with success in several countries. Implementing these or other solutions to make facilities accessible requires sufficient flexibility for schools to define their needs and sufficient access to public funds to undertake the modifications. This was at the heart of the school director's concerns and questions when he asked who would be responsible for Firuza's son. Amid a great deal of misinformation from medical and education specialists, he exhibited a clear sense of responsibility to ensure that all of the students in school had the opportunity to learn, and he was concerned that he not violate the law as he understood it. These are valid concerns, but Firuza was not deterred, and she successfully pushed for answers.

Beyond infrastructure and the framework of the school day, the extent to which slowly evolving understanding of disability, pedagogy, and education policy, the legacy of defectology, and lack of professional development opportunities can make the road to inclusion rocky emerges as a theme from all of the cases in this volume. All of them discuss the barriers created by professionals who give parents misinformation. A child with autism is initially assessed with a hearing impairment in Kazakhstan. Teachers in Tajikistan tell a mother that disability is a health issue and could be contagious or affect the development of other children.

But not all professionals have such a negative impact. Indeed, innovation by individual educators in advancing inclusive education and a supportive policy environment is the central theme of the case by Kauffman and Popova. Both the founder of the center for children with disabilities and the director of School 13 have personal reasons for their involvement in advancing inclusion, but both were working from a map that was being

drawn as they traveled on their journey to inclusion. They sought funding from the regional government, gathered literature on inclusion and disability to answer the methodological questions that arose in classrooms, and found training for teachers. The spirit of community innovation and risk-taking also infected the students, as demonstrated by the incident when they wanted to help their classmate with impaired mobility but did not know how and ended up falling down together.

Similarly, the founders of Umut Nadezhda in the case by Kokina and Bagdasarova had little experience as special educators or school administrators. Yet their center is the first in Kyrgyzstan to provide inclusive education for a mixture of children with severe, multiple disabilities and normally abled children through a model of “reverse” inclusion. The legacy of segregated systems in this region means that students are often grouped by disability type. However, at Umut they have found that teachers in mixed-ability classrooms are more likely to be flexible and to develop the skills to personalize their teaching instead of focusing on a rigidly prescribed set of methods. The example demonstrates that successful inclusion leads to increased opportunities for development for all children.

Equally important, many of these cases argue for the importance of professional learning communities within schools. For inclusive education to be successful, especially in the face of the learning challenges and severely constrained resources of Central Asia, it is vital that schools work in a spirit of collaboration and support that demonstrates the same respect for teachers as for the children in their class. The discussion club for teachers at Petropavlovsk School 13 and the intense weekly meetings and training sessions at Umut Nadezhda are both examples of this type of mutual professional support and mentoring among teachers in practice.

Sustainability is a theme that is explored by Hartblay and Ailchieva. When the external funding for an inclusive education project in Northern Kyrgyzstan came to an end, the initiative continued to develop because of the professional commitment to making it work. Such an example demonstrates the power of small-scale “seed money” projects in the development of inclusion. Many of the most successful examples of inclusive practice in the West are the result of small-scale initiatives involving professionals, parents, and policy-makers working together, which continue after the initial funding runs out because those involved have learned new ways of working.

Encouraging the expansion of successful innovative programs for children with special education needs was one of the central recommendations emerging from the OECD’s research report in Central Asia (OECD

2009). This recommendation is still valid, and these cases provide evidence for local models of important steps toward more inclusive education systems. Some of the pedagogical practices and NGO-provided services may not match current Western expectations for inclusive education, and almost all of the cases have examples of classroom practice that could be described as exclusionary. However, it is important to remember that these cases represent first steps on the path to inclusion. Rather than incorporating these models wholesale into national education policy and declaring success, policy-makers must find a way to bring the lessons that are emerging from these programs into broader discussions of education reform so that their philosophy and experiences are shared with others throughout the system.

It is also important to remember that education systems and state agencies are not monolithic. There is significant room for variation in attitudes, experience, and expertise within them, as the case on Ashyk Alem in Kazakhstan demonstrates. Markova and Sultanalieva explore the history of NGOs as institutions in Kazakhstan since the disintegration of the Soviet Union and their subsequent relationship to the government. Perhaps because systems of social service delivery did not experience the crisis of the 1990s as deeply as in Kyrgyzstan or Tajikistan, NGOs have not replaced or filled the gaps of nonexistent state agencies, as Bagdasarova and Kokina describe in Kyrgyzstan. Instead Markova and Sultanalieva found that state agencies in Kazakhstan established NGOs to get around the inflexibility and funding constraints of government agencies.

These case studies are not presented as blueprints of perfect practice to be replicated elsewhere in the region, but rather as real examples of the messy struggle for inclusive education. We hope that they will help to illuminate the complex and contested terrain on which attempts to educate all children are currently being enacted. We also hope they will place on record the achievements of those who have worked to make inclusive education a reality for many children and their families. Finally, perhaps these case studies may help in a small way to create a policy climate more supportive of the education of children who may have been excluded in the past.

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Tradition, Stigma, and Inclusion: Overcoming Obstacles to Educational Access in Tajikistan

Benjamin Gatling and Manzura Juraeva

“Now I’m halfway along the road. I don’t want to, nor can I,
stop again... No, I’m not halfway along the road. I’m still at
the beginning of the road, and it’s a very long distance that
I have to cover.”—Firuza*

Introduction

Firuza always knew that her son had the ability to succeed in school. Indeed, she knew that without a rigorous education, he would be relegated to a life of poverty, and without the financial support of her children in her old age, she too would struggle to survive. But the director of the village school, outside the Tajik capital, Dushanbe, refused to allow her son, Umed, to study with his peers. The only thing that distinguished Umed from other boys his age was that he needed assistance walking long distances and sometimes did not have full control of both hands. Four years later, Umed is thriving in the third grade of his village school, earning top marks in all his subjects and maintaining good relationships with his classmates.

Umed’s inclusion in mainstream Tajik schools was not accomplished without effort. Indeed, Firuza had to overcome numerous barriers to achieve equal opportunity for her son. Her case is further distinguished by the specific means and methods of her achievements. As a single mother lacking much formal education and without financial support, she was able to circumvent traditional gender expectations and the social shame and stigma of having a child with disabilities in rural Tajikistan. In addition, with the assistance of Tajik civil society organizations, she learned how to navigate Tajik bureaucracy and gained a vocabulary of basic rights in order to advocate for her child. Beyond calling appropriate attention to

* The names in this case study have been changed.

the heroic dimensions of her efforts, her case also highlights the remaining social and structural obstacles to inclusion in Tajikistan and the potential of Tajik civil society organizations and individual parents to effect social transformation from within. Firuza demonstrates how even when significant challenges exist, parents can and do have the opportunity to work on behalf of their children and are finding real success.

Here we examine how this one woman overcame cultural and social obstacles, including Tajik gender norms, family influences, social stigma, and institutional and attitudinal barriers, to enroll her son in primary school. This case study offers potential lessons and avenues for inclusion and helps define the remaining challenges for education for all in Tajikistan. We first discuss some initial problems related to issues of shame, stigma, and gender expectations posed by cultural norms in rural Tajikistan and how Firuza was able to marshal culturally appropriate means to circumvent them. We then investigate the institutional and attitudinal barriers of educational inclusion that Firuza encountered and highlight the methods she used to work them in her favor. Lastly, we consider the remaining challenges Firuza and Umed may face as Umed progresses through school and beyond and offer some recommendations for their amelioration.

As co-investigators, we completed research for this case study in the fall of 2011 in and around the Tajik capital, Dushanbe. Structured, semi-structured, and unstructured interviews and participant observation were conducted at the Dushanbe office of the Psychological-Medical-Pedagogical Commission (PMPC), the office of the Association of Parents of Disabled Children (APDC) in Dushanbe, and Firuza and Umed's village in Dushanbe's extended suburbs. Study data were also supplemented by preliminary investigations carried out by Juraeva in 2010 at the PMPC and APDC in Dushanbe.

Situated in the mountains of Central Asia, bordering Afghanistan, China, Uzbekistan, and Kyrgyzstan, Tajikistan is the poorest of the formerly Soviet Central Asian republics, with a per capita income of U.S. \$700 (World Bank 2011: 12). Besides small cotton and aluminum sectors, the economy and Tajikistan's population of approximately 7 million, 73 percent of whom live in rural areas, are almost entirely dependent on remittance income from migrant workers living in Russia and other CIS countries. In 2010 Tajikistan was the most remittance-dependent economy in the world (Mohapatra, Ratha, and Silwal 2011: 3).

Education is compulsory for four years of primary school, generally from age seven, and five years of basic education, up to the age of 16 (OECD 2009: 193). State expenditure on education is low (3.8 percent of

GDP) and inadequate to meet the needs of Tajikistan's young and fast-growing population (UNICEF 2009: 1). Tajikistan's more than 3,800 schools served approximately 1.7 million children in 2008 (OECD 2009: 194), all amidst a chronic teacher shortage, with many teachers severely underpaid and lacking basic training. These problems are compounded for children with disabilities. Though the government has taken significant steps by enacting legislation in support of inclusive education and equal rights with respect to education, specialized institutions are still the primary means of delivering educational services to such children (OECD 2009: 215), and Tajikistan's chronic infrastructure problems, coupled with a medicalized approach towards disabilities, continue to hamper children's access to educational opportunity.

Gender, Shame and Stigma, and the Tajik Family

Beyond common difficulties encountered in other post-Soviet spaces in achieving education for all and full inclusion of children with disabilities in educational institutions, issues of shame, social stigma, and challenges posed by standard gender norms stand in the way of achieving educational equity for children with disabilities in Tajikistan. Issues of shame and stigma related to having a child with disabilities are, of course, not unique to Tajikistan. Indeed, similar factors inhibit education for all in diverse environments across the greater Middle East, South Asia, and Central Asia (Brown 2005, Mitchell and Desai 2005).

When Umed was born, there was little indication that he or his family would have difficulties. But at about the time her son was a little over a year old, Firuza began to notice that he had difficulty with movement in his legs and arms. She and her husband took him to specialists in Dushanbe, the Tajik capital, where he was initially diagnosed with polio. Later diagnoses pointed to cerebral palsy as the likely cause of his difficulties. Shortly after, her husband went to work as a migrant in Russia and rarely ever sends remittances home; approximately five years later, he still has not returned.

Misdiagnosis and the structural challenges of the post-Soviet Tajik medical establishment were not the only obstacles. Firuza's de facto estrangement from her husband left her dependent on her husband's relatives in the village. However, they too broke off contact and left her without sufficient financial means and support, implicitly reacting to the shame associated with having a child with disabilities in their family.

Thus the result of Umed's (mis)diagnosis was ostracism from her marital family.

In traditional Tajik marriages, the new bride leaves the control and protection of her natal family and becomes a part of her husband's family, falling under the control of her husband's male relatives (Harris 2004). For Firuza, the pressures of conforming to traditional Tajik gender ideals were perhaps even more pronounced. She and her husband's family were originally from the Garm region in the mountains of northern Tajikistan, an area of more conservative values and traditional gender expectations (Harris 2004, Heathershaw 2009). In her own words, she had always been very submissive and rarely ventured outside the walls of her family compound prior to her marriage. And even then, she attended school only up to the fourth grade. Firuza says, "I hadn't seen any of the city [Dushanbe]. The first time I went out [with Umed], I didn't even know how to go by bus." Her husband's relatives in particular were pleased by Firuza's modesty prior to the birth of her son. However, the birth of a child with disabilities changed her social status and threatened her husband and his family's "honor."

Many traditionally minded Tajiks maintain a folk belief that congenital abnormalities are the result of the birth mother engaging in sexual relations outside of marriage or other behavior considered "antisocial." Thus the community often sees a child disabled from birth as "evidence" of such behavior. The community also often concludes that the males in the child's family have lost control of the birth mother, be she their wife, sister, or daughter. This perception is severely damaging to Tajik concepts of male honor (Harris 2006). According to Firuza, her virtual abandonment is her husband's response to this potential shame, and his remaining in Russia prevents him from having to face this situation.

One parent of a child with disabilities in Dushanbe likewise said:

Maybe five percent of children with disabilities study in school, because in the villages they are ashamed. They think that if they see my child, no one will marry my daughter. I would tell them, "Look, I have a disabled child. Look, my child reads. You won't always be alive. The child will need to work. You think your other children will look after your child? If he can read, he should, so that when he gets older he can do some work. He can get married. If he stays at home, all of his abilities will go away." The problem is the parents. The children are always agreeable. They want to be together with healthy children, but the parents are ashamed.

Like Firuza, another parent says that her family was initially opposed to sending her child to school. She says:

At first my husband was against this. My mother-in-law created even more problems [than him]. That's the tradition. They said it won't get better. "Why are you taking him there [to school]? It won't get better."

While her husband's family has provided Firuza with a place to live, albeit in extremely tenuous circumstances with the possibility of eviction always looming, they offer little other support, financial or otherwise. The primary determinants of Firuza's precarious financial situation, her social isolation, and Umed's exclusion from the local school were due primarily to traditional Tajik issues of shame and family stigma and traditional Tajik gender norms. However, cultural factors were not alone in preventing Umed from achieving full social inclusion. Perhaps even more daunting were potential institutional and structural obstacles to Umed's attainment of educational opportunity.

Institutional and Attitudinal Barriers to Inclusion

By the time Umed had reached school age, Firuza had resigned herself to the fact that Umed would never enter school. However, a teacher at the local school encouraged Firuza to enroll her son. She said that Umed was capable and smart and that she would help Firuza take him to the village school. When the new school year began, Firuza finally worked up the courage to take him with the other children entering the first grade. She took him every day for two weeks, not fully expecting him to be accepted, until the school director eventually told her that Umed could not study with the other children.

The school director explains his initial reluctance to admit Umed as a pupil in terms of issues of responsibility:

The school is a place for healthy children. If they are healthy, we'll accept them. Our pedagogy is for healthy children, not for special children. Our teachers aren't prepared to teach disabled children. They've been trained in standard pedagogy and psychology. It's possible that we would accept other children, if they have documentation from doctors. Here it's like an experiment [with Umed]. Teachers ought to receive a larger salary if they are also to educate disabled children. It makes a difference how much the children know. Parents have to have permission. They try to make it the responsibility of teachers. The law says the school is a place for healthy children, the healthy. We have special places for disabled children. As long as we have a recommendation from a doctor and they aren't too disabled, we can accept them. Someone must take responsibility for the child. He may fall. He may get hurt. Of course, it's not always like this with Umed. [In this case], we got advice from doctors. They took the responsibility.

The director declared that Umed could not study until the director received written permission from the district office of the Ministry of Education that would absolve him of any responsibility if other children became ill as a result of his attendance or if Umed fell. Furthermore, he maintained that if Umed was injured while on school property, the director would be to blame. For the director, Umed was not “healthy,” and his school was a place for healthy children. For children like Umed, there were special boarding schools.

Unwilling to accept the director’s refusal, Firuza sought to obtain permission from district education officials. However, her conservative in-laws would not allow her to navigate the sometimes arcane rules of the Tajik bureaucracy alone, and they were unwilling to help her themselves. Firuza turned to her father. He agreed to go with her to the district office of the Ministry of Education. Through a family friend who worked in the office, they discovered that they needed to take Umed to be evaluated at the Psychological-Medical-Pedagogical Commission in Dushanbe. Firuza’s father balked at taking her to the office and told Firuza to forget about it. Reacting to the potential for shaming talk and gossip, he says, “When the council didn’t give her permission and told her to go to the PMPC, I said no. It’s not good if I come down here and pick her up. They’d say, ‘Why are you doing that?’”

Her father also says he did not believe that the commission in Dushanbe would rule favorably for her and did not want her to be disappointed at an unfavorable result. He felt that if therapy were required, they would not have the means necessary to take him to therapy visits or to other necessary consultations. Determined to enroll Umed in school, Firuza broached traditional gender norms and decided to go against the wishes of her father and husband’s family and went to the commission.

The PMPC acts as the primary means whereby parents and children with disabilities interact with various organs of the Tajik government, though no fewer than three other bodies also have some oversight of disabled persons’ access to state benefits, work opportunities, or other social services (OECD 2009: 190–191). At its core, the PMPC serves the purpose of providing consultations to parents of children with disabilities. However, the PMPC more prominently acts as the primary gateway for parents of children with disabilities to gain access to state benefits and the necessary documentation required for almost any interaction with Tajik officialdom. While the PMPC’s purpose may be primarily consultative in nature, its work is also medical, as it provides therapeutic and other medi-

cal and diagnostic services as necessary. Indeed, the Dushanbe office of the PMPC shares office space with a hospital.

After PMPC staff examined Umed, they initially recommended him for home study due to his difficulties in walking without assistance. They then referred Firuza to her local education commission, which would bear the responsibility of sending teachers to his house to teach him at home. Firuza emphatically refused their recommendations. She knew that the level of education Umed would receive would be subpar if indeed the commission sent any teacher at all. Furthermore, she found it absurd that he should study at home, when the local school building was next door to their apartment building. While he needed assistance walking to school, which she was willing to provide, he needed only to walk down the stairs of their apartment building and into the school yard. Firuza wanted Umed to go to school with other children. So Firuza began to take Umed three times a week to the commission for physical therapy.

Beyond the consultative, therapeutic, and diagnostic aspects of the PMPC's work, the PMPC's offices also act as a networking hub for the greater Dushanbe special-needs community, perhaps one of the only spaces in which many parents of children with disabilities have the opportunity to speak and compare notes with one another. Officials at the PMPC referred Firuza to the Association of Parents of Disabled Children.¹ The association was founded in 2007 by the parents of a child with special needs who sought to inform other parents of their legal rights and to promote the integration of children with disabilities into Tajik society. With the support of the Open Society Institute Assistance Foundation office in Tajikistan, they consult with parents on their rights before the law, offer support for parents in managing issues related to depression, and inform broader Tajik society about the association and its activities through various media and public events. They also hold monthly seminars on topics beneficial to parents of children with disabilities and offer weekly tutoring to prepare children to enter mainstream schools. Sabohat, the founding director, says:

There are about 3,000 parents of children with disabilities registered in Dushanbe. When I founded the center, not one of them knew their children's rights. No one knew their own rights. My husband is a lawyer, so we explained to them their rights. Now 50 [the members of the association] know, but the other 2,950 don't know. Society doesn't see our children. That's why they don't accept them. If we brought them out, they would accept them. Parents don't want to send their children to special boarding schools. They want them to stay with them. We say they have the right to study in the school.

¹ See Whitsel and Kodirov in this volume for more information on the association.

The Association of Parents of Disabled Children inculcates parents with a discourse of rights and the law, even though they find that educational officials, teachers, and school directors are unaware of legislation regarding children with disabilities. Parents insist on a discourse of legal rights specifically in regards to a draft law on the “National Concept of Inclusive Education for Children with Disabilities in the Republic of Tajikistan for the Period of 2011–2015” adopted in April 2011 (Ministry of Education 2011). As such, one member of the association says:

I found out about the association at the PMPC. They answer our questions. They tell us about our rights. We’ve got our own rights. They told us about the new law. Schools wouldn’t accept our children. I went to put my daughter into school, they wouldn’t take her. Then I came here. I learned about my rights and went back and talked to them [at the school]. We told the director that the world is including [special-needs] children in school. In Tajikistan this plan has begun.

This recent initiative has empowered parents in their interaction with educational officials. The parents speak of its importance in defining the Tajik state’s approach to educating their children and its rhetorical capacity for convincing school directors of their children’s educational rights. The document includes few action points and still fewer items of tangible improvement and instead works as a framework for future government action, pointing towards directions for future improvement. In spite of these limitations, the psychological impact of state endorsement is a significant, positive step in including children with disabilities in the Tajik educational system, as parents now can point to governmental support for their actions. The more significant challenge is that educational officials, school directors, and teachers are unaware of its enactment. The Ministry of Education has neglected to educate those under its jurisdiction about these children’s legal rights and schools’ responsibilities for accepting children like Umed. As such, the Association of Parents of Disabled Children sees public education as a vital component of what it does. Sabohat says that one of the main goals of the association is “the integration of people with disabilities into the community by informing parents and informing society.”

Firuz took full advantage of the PMPC and the advice and guidance of the parents’ association. She attended their seminars on rights and navigating bureaucracy in addition to taking Umed to regular school preparatory lessons. According to others at the parents’ association, what distinguished Umed from many of the other children who gathered at the association was that he was mentally “well.” The discourse of “wellness”

specifically in regards to mental ability is what other parents believe allows Umed to integrate and be included in standard schools, unlike children with more severe disabilities. Thus beyond the legal sphere, they reframe the discourse of “health” that the director deployed in his tactics to prevent Umed from attending school. One parent says:

The director said, “The school is for the healthy. He’s not healthy.” He said that Umed couldn’t walk independently. “What [would he do] about the snow?” We came and introduced the children to Umed. We said, “He’s like you. He’s healthy. He’s smart. He just can’t walk well. You should help him carry his books, help him go to the bathroom.” A few months later, when we went, we found that most of the students had become friends with him.

From the time of Umed’s diagnosis as a toddler until the present, discourses of “health” have figured prominently in the ways the state apparatus, and even other parents, have interacted with him and his mother. This medicalized discourse of disability pervades the entire educational system, in a parent’s encounters with the PMPC, what other parents say at the parents’ association, and the school environment. The school director explains his initial reluctance to accept Umed as a pupil by saying that the school is a place for “healthy” children. Furthermore, his stated worries about Umed’s attendance are all related to a medical/health framework. For example, he says Umed may expose the other children to potential contagions or that Umed’s “condition” may cause him to fall and get injured at school. His duty as school director, as he sees it, is to preserve the school environment for “healthy” children, while he believes that special boarding schools are responsible for managing Umed’s educational achievement and health. In addition, the primary governmental conduit for parents of children with disabilities works within the same discursive field. Rather than pushing Fizuza to help Umed achieve his observed educational potential, the resources the PMPC provides are primarily medical, diagnostic, and therapeutic. While many of the PMPC’s clients’ needs may fall within this mandate, for children like Umed, the PMPC’s diagnostic resources do little to assist parents in attaining any measure of educational equity for their children.

Interestingly, parents at the parents’ association work within, but also complicate, this discourse of health. While school directors or officials at the PMPC may insist on categorizing their children as outside the “healthy” group, parents often speak of how their children are indeed “well” and thus by extension capable of participation in mainstream Tajik schools. That is, for many parents, specifically with respect to their chil-

dren's attendance in local schools, health becomes equated with mental ability. If a child has the mental capacity to take part in schoolwork alongside his peers and without special accommodations, then the parents judge the child to be "well" irrespective of any physical limitations. It is precisely these factors that other parents at the association credit for Umed's success at inclusion in his village school. While the parents' reappropriation of this medical discourse of health may enable them to position children such as Umed towards academic success, this discourse and its tactics may also limit the potential for children with more severe mental or physical challenges to enter their local schools.

After the director and assistant director of the parents' association helped prepare her, Firuza took Umed back to the school at the beginning of the next academic year, armed with a discourse about their rights, paperwork from the PMPC, and the force of argument. Still, the director refused to accept Umed as a pupil and deflected their arguments. Instead, he claimed that the documentation that Firuza received from the PMPC and the preparation for school Umed had completed did not give him permission to enroll at this specific school, but just a school in general. And thus, he said, he was not obliged to accept Umed as a student at his school. When Firuza returned with the director and assistant director of the parents' association in tow and threatened the school director with legal action if he did not enroll Umed in school, he finally relented. However, their fight was not over. The school director responded by placing one additional obstacle in their path; he moved Umed's first-grade classroom to the second floor of the school.

In the end, the director conceded. The combined pressure of the parents' association, Firuza, and the assurances of a friendly teacher convinced the director to finally accept their demands. Yet one further attitudinal barrier still had to be overcome. While Firuza had the support of one teacher, not all of the school's faculty or pupils supported her efforts. One specific teacher singled out Umed for extra punishment due to his handwriting. Umed's disability at times prevents him from having full control of both of his hands. After Firuza found out, with a new assertiveness cultivated at the parents' association, she quickly came to the school to complain about her son's treatment. She says:

One day, Umed came home crying. I asked him, "What happened? Did you fall?" He said, "No." "Why are you crying?" His classmate said that the Russian teacher hit him. I went to the teacher and said, why did you hit Umed? She said, how did you know? I said, "Why'd you hit him?" "He couldn't read and write Russian." She apologized to Umed. Since then, no teachers have hit him. There haven't been any problems in school.

In Firuza's case, the parents' association provided the primary means for her to gain assistance in enrolling her son in school. Once she had chosen to circumvent the strictures of her husband and her natal family's wishes, the parents' association was the forum that allowed her to gain the assertiveness, legal empowerment, and emotional and logistical support necessary to follow through on her initial plans to put Umed in her village school.

Future Prospects

Firuza's efforts to enroll her son in her village school succeeded, and Umed continues to outperform his peers academically, consistently receiving top marks in all of his subjects. Though Umed has seen success in his schoolwork and in relations with his schoolmates, he still faces further challenges as he progresses through school. In the Tajik educational system, a teacher remains with the same pupils from the first grade until the fifth grade. Afterward, students rotate through multiple subject teachers yearly. Firuza argues that the compassion and understanding of his current teacher have given him an environment in which he can thrive. Likewise, his teacher says, "If new teachers are strangers, there will be problems in the future. They have to be compassionate to him. I didn't want him to be separate."

Firuza maintains that her efforts are not over. She says:

Now I'm halfway along the road. I don't want to, nor can I, stop again... No, I'm not halfway along the road. I'm still at the beginning of the road, and it's a very long distance that I have to cover.

She will have to endeavor each year to provide Umed the opportunity to study with his classmates. Beyond that, Firuza worries for her son's future after school. Even if he makes it through graduation in the village school, what does his future hold? Limited economic opportunity in Tajikistan forces up to a third of the Tajik workforce to migrate to Russia to seek work, most of it in construction and other manual labor (Mohapatra, Ratha, and Silwal 2011). When he is finished in school, Umed will not be able to work as a migrant laborer in other CIS countries. Firuza says:

He needs to study mathematics, so he can be a banker, for instance, or even a diplomat. Whatever it is he wants to do, he should do. I want him to do everything. I've done so much for him. I want to take him to the end. I didn't want to put him into a boarding school. He will go forward.

Conclusion

Firuza's success in putting Umed in school illustrates how traditional gender norms, familial stigma and shame, and even some issues related to poverty can potentially be overcome with determination and the assistance of Tajik civil society organizations and do not necessarily have to act as social determinants of a child's educational opportunity. However, numerous institutional and attitudinal barriers remain.

In this instance, the school director still believes that Umed is a unique case, and inclusion of other special-needs children in his school is far from certain. Indeed, he is still concerned about his and his school's responsibility towards such children. He and many other rural school directors are not aware of the draft law on inclusive education and the discourse of children's rights with respect to equal educational opportunity. While the school director's objections may seem without substance and merely rhetorical resistance, and while the corporal punishment by Umed's Russian teacher may seem particularly cruel, the fact remains that broad public education about the nature of disabilities is critically absent. Beyond the shame and stigma attached to families who have children with disabilities, public discourses of health come to the fore. Indeed, the school director's insistence that Umed's cerebral palsy may be contagious and that his presence in the classroom may put other children in unnecessary harm indicates that broader public education is necessary.

Further, while Firuza's efforts resulted in her son attending the local village school, there still remain significant challenges to his full inclusion in broader Tajik society. It is yet to be seen how he will fare in subsequent grades and after graduation. His grandfather says:

A lot of people still say, enough already [don't keep him in school]. This isn't fortune-telling. It's true if there's help from somewhere. We'll help him as long as he needs it. He has to succeed. We'll help him, but he has to try.

While he has the support of his mother and her father, Umed still faces an uncertain future. Many of the recommendations of the OECD 2009 report on students with special needs and people with disabilities in Tajikistan have yet to be implemented (235–244). New legal frameworks have benefited specific actors with knowledge of their enactment, such as Firuza and other members of the parents' association. However, their implementation still lags, as educational officials, school directors, and teachers lack knowledge about what the law entails and the skills to uphold its provi-

sions. Furthermore, in the post-Soviet era, the state's medicalized approach towards children with disabilities continues to inhibit these children's participation in the educational system, even as some parents like Firuza are able to redeploy its rhetoric. The determination of individual parents like Firuza has resulted in laudable but numerically limited results. Sabohat, the director of the parents' association, says the association was successful in enrolling 18 children in mainstream schools this past year, but thousands of other children remain outside the bounds of educational institutions, and the Dushanbe PMPC estimates that it has knowledge of fewer than 10 percent of the children with disabilities within its geographic jurisdiction. Firuza's case illustrates how barriers to inclusion can be overcome, but, as Firuza argues, the journey to educational achievement for all in Tajikistan has only just begun.

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Out of the Shadows: The Work of Parents in Inclusive Education in Tajikistan

Christopher M. Whitsel and Shodibek Kodirov

A knock at the gate breaks the noises of village life on a crisp fall day. A busy mother sorting rice sends her son to the gate to see who has come. The woman at the door is a stranger who begins asking questions about whether there are disabled children in the home. She is doing a survey in the area to count the number of disabled children and is asking basic questions about the children. The mother is instantly ashamed and asks, "How did you find my house?" "We asked the neighbors, and they mentioned a disabled child lived here," the stranger responds. The mother demands, "What do you want to know?" and the stranger replies, "Only basic questions to know who is in the area." It turns out that the woman is a representative from a local parents' association of children with disabilities. The stranger mentions, "We also have information we can offer, and our association works with parents to help their children." It is the first time that the mother has heard of any such organization, that anyone in society would care to help her disabled child. Usually, it is considered a shame for the family to have such a child, or at the very least a burden. She wonders what good a parent organization is and if it would improve her child's life.

This was a scene repeated in several villages and in cities across Tajikistan as representatives from various parents' organizations recently carried out surveys of the incidence of disability. The goal was to learn how many children with disabilities there were in their neighborhoods, because the available data are insufficient. One of the reasons data are unreliable is that many parents do not register the birth of children with a disability, even though doing so could mean that they get state support. Thus the number of disabled children registered by the state is much lower than actual rates, making it difficult to assess the need.

Parents' associations across Tajikistan have helped increase awareness of the need for inclusive education, often through simple tactics. Many parents' associations in Tajikistan have two primary goals. First, they teach parents about the value of all children and the importance of bringing their children out into society. Second, they inform parents of their rights and their children's rights. Equipping families in these areas leads to empowered parents, inclusive schools, and ultimately a more inclusive society.

To demonstrate how these changes are occurring in society, we highlight the case of the Association of Parents of Disabled Children (APDC) in Dushanbe. We first review the context of Tajikistan, then provide a description of how the organization was founded and some examples of the work that they do. This is followed by excerpts from a focus group discussion that illustrates the changes taking place as a result of their work.

The Context of Tajikistan

Today's Tajikistan occupies mountainous territory on the southernmost edge of the former Russian and Soviet empires. China lies on its eastern border and Afghanistan lies to the south. It was conquered by Russia in the late 19th century and gained its current borders in the 1920s, when the Soviets delineated the territory of previous emirates and khanates into republics supposedly organized as ethnic homelands of the Kazakhs, Kyrgyz, Tajiks, Turkmen, and Uzbeks.

Once Soviet rule was established in the country, a large-scale modernization project was begun. Many kilometers of roads and railways were built. Production was mechanized. Hydroelectric dams were erected in the river beds. Russo-European culture was actively promoted in the hope of supplanting traditional cultural norms viewed as backward by Soviet ideologues.

The current education system was established in this time of great modernization. Literacy rates at the beginning of the Soviet era were estimated to be well below 5 percent of the adult population (Pennar et al. 1971). Within 20 years of Soviet rule, leaders were boasting that they had built schools in every village and that universities had been established (Negmatullaev 1949), although scholars say the conditions of schools were often deficient and that even today there is not a school in every village. Nonetheless, estimates at the end of the Soviet era put adult liter-

acy rates close to 100 percent, and a majority of Tajikistan's citizens had a high-school degree or higher.

Tajikistan gained independence from Soviet rule in 1991. The first decade of independence was characterized by economic decline, as was common in the region, and political instability. In 1992 the political instability led to a short-lived civil war. The violence was concentrated in a few areas in the southern regions (Khatlon and the Region under Republican Subordination, and Dushanbe), but the entire country felt the loss, and the central government was not able to manage the regions. Peace accords were signed in 1997, and the government began to centralize its control of the regions.

Civil society is fairly underdeveloped in Tajikistan. This stems partly from a patriarchal cultural orientation that emphasizes respect for elders and partly from fear of the political chaos that resulted in the civil war. There have been no significant civil protests of any type since the end of the war. The civil society organizations that do exist focus mostly on education and social services sectors (Yusufbekov et al. 2007). The central government has increased its restrictions on civil liberties, citing recent military skirmishes with "Islamic extremists."

The second decade of transition had a more positive trajectory than the first. Although Tajikistan remains one of the poorest countries in the world, peace brought economic development, and the country witnessed growth rates of close to 10 percent of GDP for several years (World Bank 2009). A large portion of the growth in GDP in recent years has come from migration. In 2007 approximately 20 percent of the working-age population was registered as working in Russia (World Bank 2009), and in 2008 remittances sent through official means accounted for close to 50 percent of GDP (UNICEF 2011).

Trends in educational attainment since independence mirror the economic and political trajectory. In the first decade of transition, educational attainment fell. Educational inequality increased between rural and urban students, girls and boys, Tajik and minority students, and the rich and the poor (Whitsel, forthcoming). The second decade of independence has seen an increase in the number of students attending school, although important differences among groups remain. This is especially the case for girls, who continue to be at a disadvantage.

Tajikistan's Educational System

As with other countries in the region, Tajikistan's education system resembles the Soviet system. Primary education begins at age seven and continues for four years. Continuing the Soviet tradition, students remain with the same teacher and group of students throughout all four years of primary education. General secondary education is an additional five years, and children typically begin at age 10 and complete ninth grade at 14 years of age. Students continue to study as members of an established class group throughout their secondary education, but subjects are taught by several teachers who are specialists in various subject areas (such as literature, history, and physical education). While other countries in the region require study until the 11th grade, compulsory education ends at ninth grade (age 14). Though students receive a certificate at this time, it is considered an "incomplete secondary education." There are a significant number of school leavers at this transition, especially among girls. After ninth grade, youth can choose to complete their secondary education in either a vocational school (usually three years of study) or in the academically oriented secondary school (two years of study). University education is open to all graduates of either school type and continues for five years.

There is centralized control of curriculum planning, accreditation, teacher training, and financing standards at the Ministry of Education. However, the capacity of the Ministry of Education is limited by lack of funding and the multiple mechanisms of control over schools among regional administrations (OECD 2009). Management difficulties also arise because of the heritage of multiple ministries that have the authority to monitor educational institutions. For example, the Ministry of Labor and Social Protection has the authority to establish vocational schools and universities to train specific types of employees. In our case this is significant, because administrative authority over institutions that serve children with disabilities lies not only with the Ministry of Education but also with the Ministry of Labor and Social Protection and the Ministry of Health (OECD 2009).

The education system was severely weakened by the economic crisis and political instability of the post-Soviet transition. During the civil war many schools received no funding or direction from the central government. Financial difficulties continue to this day, and many schools have demanded that families provide financing for classroom supplies, heat, or even to supplement wages (Whitsel 2011). The cultural orientation of

deference to authority in society means that school authorities are rarely questioned and often means that parents are not empowered to intervene in school issues. The recently passed Law on Parents' Responsibilities codifies the relationship dynamic, as it mandates that parents not interfere with teachers' "professional" work, while at the same time making demands that parents ensure that their children are dressed according to traditional standards, not out late at night, and not bringing cellular phones to schools.

Inclusive Education in Tajikistan

While Tajikistan has made great strides in the past decade toward education for most children, this is not the case for children with disabilities. The exact number of children served is not known, but it is estimated that only 13–25 percent of children with disabilities are receiving any type of education (OECD 2009; UNICEF, forthcoming). The current system favors institutionalization but also offers families the choice of homeschooling or, on rare occasions, education in segregated classes within general schools. Even fewer opportunities exist for children with disabilities to attend their neighborhood school and join a mainstream class, although the number is slowly growing.

An Expert Group of the National Commission on Child Rights conducted a situation analysis on children with disabilities and cited social prejudice as the most significant barrier to greater inclusion (UNICEF 2006). Children with disabilities are mostly removed from contact with the larger social world. Parents often hide their children with disabilities in their homes, as in the example in the introduction of this chapter. If parents do seek medical help, officials generally recommend sending children to a boarding school or sanatorium, which is often very far from their homes.

The cultural norms of exclusion have been institutionalized in legislation, state structures, and the educational system. Evidence of this is seen in the very definition of disability, which is based on the medical approach. Children's disability is defined as "a permanent social disadaptation resulting from a chronic disease or pathological condition and seriously restricting the possibility of integrating the child in the environment suited to its age" (UNICEF 2006). Note that even the definition includes language about the restrictions of integrating peers. The newly adopted "Concept Paper for Inclusion of Children with Disabilities" continues

with the medical approach seeking to rehabilitate children and emphasizing prevention, but it contains more language encouraging adaptation of the current system to meet the needs of children with disabilities.

Families that do choose to seek a diagnosis and help for their children face several layers of bureaucracy. Responsibility for children with disabilities falls under three distinct ministries: the Ministry of Labor and Social Protection, the Ministry of Health, and the Ministry of Education. Initial diagnoses of disability come from Medical Consultation Commissions, usually located in a local polyclinic and under the jurisdiction of the Ministry of Health. To access educational services, parents must go to a Psychological-Medical-Pedagogical Commission (PMPC) for a consultation. PMPCs employ defectologists, speech and hearing therapists, special-education teachers, and social workers. Currently there are only four PMPC centers in the country, making it difficult for rural residents to access services. The majority of consultations in PMPC centers result in referrals to institutions, and very few receive encouragement, or certification, to pursue inclusive education. The PMPC of Dushanbe seems exceptional in this case, as international organizations have conducted significant training with center staff in order to reduce the number of children who are institutionalized (OECD 2009).

Because exclusion has been the norm, the human and physical resources of the education system were not planned with inclusion in mind. School personnel have not been trained to include children with disabilities within their programs. There is no curriculum for children with disabilities. Schools were not designed to be accessible by people with disabilities. Efforts to retrain personnel, plan curricula, and remodel buildings are hampered by the economic difficulties the country faces and the management capacity of the government. However, it should be noted that the newly adopted “Concept Paper for Inclusive Education” includes plans for reforms.

It is difficult to ascertain how many children with disabilities are in mainstream classrooms. Because responsibilities for children with a disability fall to three different ministries, no central database exists. The existing information suggests that numbers are minimal. The Association of Parents of Disabled Children reported placing approximately 10 children in schools in Dushanbe in 2008. Other parents’ associations report similar efforts, but with varying success rates. Kindergarten 151 in Dushanbe works with special-needs children to prepare them for school, but there is no record of the number of students they have served. Similarly, Save the Children piloted a community education project that em-

phasized education for all children and included children with disabilities, but the number of children with a disability who were included is unknown. Several other organizations have also sponsored projects promoting education for children with disabilities.

Association of Parents of Disabled Children, Dushanbe

Parents' associations across Tajikistan are working to change society's stereotypes of people with disabilities and demand a place for their children in society. The most prominent is the Association of Parents of Disabled Children in Dushanbe, led by Sabohat, the mother of a child with disabilities. The story of the Association began with the birth of Sabohat's daughter with disabilities. When her daughter was born, the nurses and doctors explained that the child would not be able to walk and explained other aspects of her disability. For the first few days Sabohat cried, but later, encouraged by her husband, she began to learn about what rights her child had so the family could begin to navigate the government bureaucracy. The options seemed few. There were some boarding schools (*internat*), but they were far away, and the conditions were poor. She had no desire to send her daughter to an institution so far away.

Fortunately, around the time her daughter was nearing school age, a kindergarten in the city began to offer a program for children with disabilities. Sabohat was pleased that her daughter found a place in the limited program. As with most schools in Tajikistan, there was a parents' committee at the preschool. As Sabohat met with other parents and shared her knowledge of the rights of their children and their rights as parents, she was surprised to learn that several parents were not aware of their rights. After learning that there were over 3,000 children registered with a disability in Dushanbe alone, she wondered how many more parents were not aware of their rights. That was when she decided to create an official association. Several parents from the preschool joined in to help and continue to be active members.

After completing the necessary paperwork to form a non-profit organization, the Association was given a room in the state-run Psychological-Medical-Pedagogical Commission in Dushanbe to provide consultations with parents about their rights. The PMPC is the main state body that diagnoses children with disabilities. The PMPC gives the paperwork required to gain access to the various boarding schools, sanatoriums, and also benefits (pensions). The PMPC is also the agency that assesses

whether children can be served by mainstream schools. After several years of working within the office, the Association moved to its own office location in a nearby apartment complex.

Since its inception in 2007, the Association has been immensely successful. It has consulted with close to 2,000 families. Consultations consisted of a range of support and advice on social and legal issues and the rights of disabled children and their families. The Association regularly hosts social events and activities for families. They are very active with the media, sharing the basic message of inclusion for all children and promoting the value of all children. Sabohat is regularly found meeting with officials advocating for change at many levels. Although based in the capital city, the organization has conducted several seminars in various regions of the country. A network of several similar parent organizations now exists in regional centers because of the Association's work.

The Vision of the Association of Parents of Disabled Children

Our vision is that all disabled children and their families should have equal rights and be treated with dignity and respect by society.

Our Values

- 1) We believe that disabled children and their families must be accepted by society.
- 2) We believe that the state should provide more support for disabled children and their families.
- 3) We believe in inclusive education for all children.
- 4) We believe in challenging negative attitudes toward disabled children and their families.
- 5) We believe that disabled children should grow up in their own family.
- 6) We believe that disabled children and their families should have access to information and support.

Research Methods

The research reported in this case study was designed to explore the role of the Association of Parents of Disabled Children in meeting the vision outlined above. The success of the Association was noticed early on, and in 2008 Shodibek Kodirov spent time at the Association observing the daily

routines there and participating in its activities. He also held focus group discussions with parents of children with disabilities, teachers, and professionals from the PMPC. The goal of the focus groups was to ascertain parents' own ideas about inclusive education and information about parents who provide education for children with developmental disorders. The results of the original research were then drafted into an article in Russian.

A second phase of research began in 2011 with an effort to publish the work for a wider audience. A follow-up to the original research was conducted by both authors in 2011. They visited the Association again in Dushanbe and observed its daily activities in the new location. Interviews were conducted with the head of the organization, and there were several informal conversations with parents and children with disabilities.

Signs of Change

In the focus groups conducted in 2008, almost all parents reported that they first learned of the need to be involved in the process of training from employees of the Association. As Sabohat said at the outset,

learning about a child's illness, parents are looking for support from a doctor. Many parents hope the diagnosis is a mistake and seek another doctor's opinion. Many of them are looking for information about the disability in the literature on children's cognitive development or on the Internet. There is a category of parents for whom concerns have already suggested such an outcome, and the news of an obstacle to child development confirms their fears.

Sabohat's words encouraged parents, and many of them raised their heads and wanted to speak out. One mother stated:

When the doctors diagnosed my two-month-old daughter as having postpartum cranial trauma, I thought that no one but doctors could help my daughter. I've always hoped for their help and did not even know that there are professionals like speech pathologists, psychologists, and speech therapists. One wonderful day I saw on TV that in the city of Dushanbe there was a NGO called "Health." The next day I went to this center, where I met Sabohat. Then, after we received the necessary knowledge and skills, we concluded that we could create an association, which currently is working to help other parents who have children with developmental disorders.

Several parents in the discussion explained the necessity of involving parents in child development. A respected woman asked for the floor and said,

The involvement of parents is needed, above all, because the diagnosis of these children is often changed, and each time the children need special treatment. For example, if children have language development problems, then they need the help of speech therapy. On the other hand, education is a type of treatment for children with developmental disorders.

Another mother, who stood quietly, asked for the floor and said,

Parent involvement and the involvement of children in the process of learning are inseparable. The combination of these processes eliminates the fear of other children and gives parents new skills to help their children with peculiarities in the development of the learning process.

These statements by mothers mark a very different perspective of disability from traditional norms. Traditionally care for children with disabilities simply meant clothing and feeding them. Children with disabilities were often kept inside the home, hidden from outside contact. These mothers have taken the first steps of seeking intervention and, with the help of training by the Association, recognize the need for parents' active involvement in their children's upbringing. In the focus group, employees of PMPC in Dushanbe stated that every year an increasing number of parents seek specialists for the diagnosis of their special-needs child. They indicated that this is a factor in reducing the shame of parents of children with disabilities.

The latter statement above about parents' interactions with their children also indicates that there is increased interaction with other children. During the group conversation, it was intriguing to hear references to education as a way of supporting children with developmental disorders. Another mom said,

The involvement of children with disabilities in education allows children to communicate with others and integrate into society. Community provides children with disabilities the necessary skills and knowledge, helps them to overcome disturbed mental functions, and stimulates further mental development. Communication helps children with a breach of development in becoming a full member of the family and society. The only thing required from the society is to be able to understand the inner world of a child, his aspirations and actual capabilities.

The drive for full inclusion in society has pushed many parents toward the educational system. Often they encounter difficulties at the preschool level because they rarely offer inclusive groups and have long waiting lists due to a shortage of spaces. The leaders of these institutions and their

employees are not always willing to work with special-needs children. One mother said, "When my daughter was three and a half years old, she asked the head of the nearest kindergarten to take her. The head of the kindergarten responded, 'For children like your daughter there is a specialized boarding school. I cannot accept her.'" For six months, the mother went to the head of the kindergarten with a request to take her for at least a short period of time. This was to ensure that her daughter was growing up among her peers. Finally the director agreed. Every day at 2 p.m., her daughter went to preschool so she could socialize with other children. Despite the fact that her mother paid the same as other parents, some of the teachers always hid the daughter, maintaining that children with developmental disorders should not be found among typically developing children. Then she mentioned, "with the Association of Parents of Disabled Children, I learned that in Tajikistan, there is no statute on the basis of which a child with developmental disorders may not be among their typically developing peers."

Inclusion in schools is immensely more difficult than at the pre-primary level. Very few have any inclusive groups, because the previous norm was to send children with disabilities to specialized institutions or to provide in-home tutoring. School directors and teachers continue to have the mentality shared in the quotation above—that children with disabilities should be kept separate. They also cite the lack of training, specialists, and materials.

To combat the usual claims of school officials, the Association, in cooperation with the Dushanbe PMPC, implemented a program to prepare students for school, titled "First Steps to School." By 2010, 10 children had completed the program and been incorporated into mainstream classes. Another eight children are studying in the program. Parents saw the benefits of the program early on. One happy mother reported,

In November 2007 my daughter began to attend the project "First Steps to School." For two years she engaged with professionals such as a speech therapist, music teacher, social worker, and a psychologist. In all the time she learned, she started getting better. She could speak clearly, discuss pictures, learn and recite poetry, and communicate better with children. While before she was aggressive and could hit anyone or have a tantrum during a session... now she began to change and above all has become determined and does not like hysterics.

First Steps to School

This two-year project, started in 2007, worked to develop the learning skills of children with physical disabilities so they could gain access to mainstream education. The project had three main directions: improving the quality of education at institutions for children with special needs, providing consultations to parents of children with special needs on their legal rights as well as strategies for supporting their children's education, and helping children with special needs develop musical and other artistic skills.

Working with specialists from the Dushanbe Psychological-Medical-Pedagogical Commission, project staff examined 10 children in selected institutions, identified their individual needs and capacities, and developed an Individual Educational Plan for each child. The main focus of the project has been helping institutions develop and implement sessions between special-needs students and speech therapists, speech pathologists, and psychologists three times a week. These sessions occur in tandem with discussions between specialists and parents about their child's medical history, reinforcing the role of the parent as a valuable source of information and understanding about their child's needs and abilities.

In 2008, 10 children from the project were successfully enrolled in the first grade at local comprehensive schools. This success, and First Steps to School's emphasis on teaching children and working with their parents, make the project a strong model for replication.

Open Society Education Support Program, *Children with Special Education Needs in Kazakhstan, Kyrgyzstan, and Tajikistan*

Another mother responded,

My daughter has a talent for music. She asks every day about when we go to school for music. Apparently for her this is the motivation. As a parent of a child participating in the "First Steps to School" project, I have learned a great deal for myself. Now I look at my daughter as a person, not as a child who always needs my help. I think that the involvement of parents in education is very important. For example, I managed to learn the psychology of special-needs children and methods of working with them, as well as teaching methods. I always share my experience with other parents. So I can give advice to parents of children with disabilities.

These statements again demonstrate important changes in social norms about children with disabilities. Most importantly, as a result of the program, the mother sees her daughter as a person. The mother also learned skills to improve her daughter's situation as well as her own. Rather than keeping that information to herself, the mother reports sharing the information with others along with feeling confident to give advice to other parents. The mother's response contains all of the elements of empowerment—gaining knowledge, increasing self-confidence, sharing with others. As we mentioned, the traditional parental approach to children with disabilities is feeling shame and hiding them from the public. This mother is not only bringing her child into the public sphere but has a new outlook on her daughter and is sharing skills with other parents.

Teachers also participated in the focus group and demonstrated the flexibility that they must have in incorporating children with disabilities into their classroom. One teacher stated,

In school, she may soon become accustomed to the routine; it was very difficult to sit at a desk for 45 minutes, and she often went out into the corridor. But I found a personal approach. I realized that for her it is difficult to adapt to the new routine, and I just left her alone. It paid off. She began to appear less frequently in the hallway; we tried to keep asking her questions in an entertaining way, attracted her to the learning process. As a result, she has learned well. Now she has completed the first grade and knows all the letters, can read, syllable by syllable, counts to 10 and can write.

Parents fear that even if their children are successful in primary school, they will not be accommodated at the secondary level. Sabohat, head of the Association, said,

secondary schools are not ready to accept children with disabilities. First, the architecture [the lack of ramps and elevators] does not allow it. Second, the lack of highly skilled professionals working with children with developmental disorders is also a problem. But we are happy that none of the above reasons prevented our four children involved in the project [in 2008] from going to the second class.

A co-worker of the parents' association added,

teachers in secondary schools do not know the psychology of these children and methods of working with them. They often require of them what is required from other healthy children. Teachers do not understand it is a special-needs child and have no special aids for working with children with developmental disorders.

Agitated, a first-grade teacher responded,

in institutes they were not trained in psychological work with special-needs children. Teachers do not provide visual aids. In urban schools, class size is more than the norm,

and teachers work hard with a lot of children. Children with disabilities are aggressive and do not always listen to teachers. They do not want a lot of work on one task and get up during class. Sometimes they take from other children whatever they want. In general, they often interfere with everything in learning. Teachers with such low wages cannot stand such vagaries of your children.

The reaction of the teachers, although harsh, highlights the deficiencies of the current system. It also demonstrates another mechanism for change. As parents bring their children into public and demand inclusive classrooms, teachers then demand support from the system. In her comment the teacher recognizes the need for training and materials to work with children with disabilities. The demand for support now comes not just from parents but from the teachers as well.

Sabohat shared this formula for change as she described reasons for several positive changes concerning inclusive education that have occurred recently. One of the most important recent changes is the Concept Paper on Inclusive Education passed by Parliament. It provides a foundation for building inclusive education. Sabohat argued that the acceptance of the concept paper and the increasing interest of the Ministry of Education in providing inclusive education come from many sources. She explained, "Change is coming from all sides. The donor organizations are influencing change, the government sees the need, and parents are bringing their children out into society and placing them in schools. Teachers, now faced with new challenges, are demanding curriculum and training."

Conclusion

The road to inclusive education in Tajikistan seems long. Fewer than 30 percent of children with disabilities are receiving any form of education (OECD 2009; UNICEF, forthcoming). Cultural norms encourage parents to exclude their children from participation in society and often to hide them in their homes. The current education system favors exclusion through institutionalization, home education, or education in special schools or programs. Current school infrastructure, personnel, and curriculum are ill-prepared to receive children with disabilities.

The case of Sabohat and other members of the Association in Dushanbe provides an excellent example of a mechanism of change toward greater inclusion. Each parent's journey was personal and began with a desire to seek assistance for his or her children. Sabohat's journey led her

to learn more about her rights and the rights of her children. In conversation with other parents, she learned of the greater need to inform parents of their rights, and the idea for the Association was born. The Association continues with the primary function of informing families of their rights and has conducted more than 2,000 consultations with families since 2007. Their success in this sphere has also stretched beyond the city of Dushanbe, and they have held multiple seminars and workshops for parents' groups around the country.

Another key goal of the Association has been to encourage parents to include their children in daily social life. They believe that this helps disabled children to adapt to the social environment and to build the confidence of children and their parents. Members of the organization attend concerts, go to parks, and celebrate holidays together. In the summer of 2011, the organization sponsored a nationally televised concert on the national day of persons with disability. The increased public involvement of families with their children has encouraged parents to include their children in other important social events like weddings, which previously would have been unheard of. Sabohat continues to share the basic message in the national media in many formats that children with disabilities can be involved in society.

The active participation of children with disabilities in society in greater numbers has had far-reaching effects. The PMPC staff report that more and more families are registering their children and seeking help. As more and more children ask for help and families work to send their children to schools, the education system is adapting. Teachers are requesting training and an adapted curriculum. In response, the administration is drafting plans to advance inclusive education.

Due to the outreach work of the Association of Parents of Disabled Children around the country, similar conversations about inclusive education are occurring. A simple knock at the door may start a family on a journey of inclusive education as they learn the value of their child and their rights and they begin including their child in the social life of the community. As more and more parents bring their children out of the shadows, there will be greater demand for a more inclusive school and society.

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Parent Activism in Kazakhstan: The Promotion of the Right to Education of Children with Autism by the Ashyk Alem Foundation

Mariana Markova and Dilara Sultanalieva

Introduction

This chapter presents a case study of a new organization of parents of children with autism, Ashyk Alem (Open World), in Almaty, Kazakhstan. We look at how parents have come together, what has motivated them, and the ways they have interacted with the existing system of services for children with special needs (mostly health care and education) to demand the constitutionally promised equal access to education for their children. We explore the educational, social, economic, and cultural factors in the country that impact the current state policy—promoting inclusive education for children with special needs—and try to understand how to implement inclusion and reduce barriers to learning and participation. The paper suggests venues of collaboration between the state and non-governmental organizations (NGOs) using the agents of change working within the state system and within broader civil society in order not only to enhance the national system of education but also to meet the standards of social justice adopted by many other countries. The chapter will explore the opportunities that emerge when parents unite and work towards common goals by sharing some of the ideas of the founders of Ashyk Alem. Finally, we will explore the most recent developments of the civil society in Kazakhstan and the potential for empowering parents in Kazakhstan as it democratizes.

The Fieldwork and Research Methods

The goal of this case study is to explore how, in the absence of a national tradition of parental activism, parents have been able to transcend their family problems, to register an organization, and to advocate for the rights of their children to receive educational, health, and social services and have equal access to education as guaranteed by the constitution.

The field visit to Almaty was conducted in September 2011 by a local researcher, Dilara Sultanalieva (one of the three founders of Ashyk Alem), and an international researcher, Mariana Markova. The data for this case study have been collected from interviews, site visits, and two focus groups. Interviews were accompanied by participant observation. The first observation was focused on the work of the city Psychological-Medical-Pedagogical Commission (PMPC), an institution that elicited numerous complaints from parents. The second observation was conducted during a school meeting between a mother of an autistic child and a group of disgruntled middle-school teachers demanding the removal of her child from the school. (The child stayed.)

Ms. Sultanalieva compiled the list of interviewees based on her knowledge of the local stakeholders and their availability. The interviews with mainstream school directors were arranged with the help of another local expert, Larisa Popova. The NGO directors were asked to talk about the barriers to inclusive education and to describe their experiences of children with special needs. Four parents of autistic children, who participated in the activities of Ashyk Alem, were asked to share their child's educational trajectory, specifying the points where they had to struggle with the system and express their ideas about the role of a parent organization. Parents were also asked to describe the most memorable activities organized by Ashyk Alem.

The researchers obtained firsthand information on the barriers to inclusive education for children with special needs at local schools through two in-depth interviews with school directors. The interviews were unrecorded and anonymous to ensure that the directors would feel free to express their opinions without concern for their positions. School directors were selected because parents of autistic children who succeeded in placing their child into a mainstream classroom negotiated the placements in their schools with the directors. The researchers took notes, and then the interviews were transcribed. All the names of the children described below were changed to retain their full anonymity. However, the names of the schools that admitted children with autism and piloted inclusive education have not been changed.

The Country Context

On September 16, 2011, while we were conducting research in Almaty, the former capital of Kazakhstan, the country celebrated the 20th anniversary of its independence. Over the weekend, the central square of Almaty (which means “City of Apples” in Kazakh) hosted an Apple Fest, a city fair, all-day music performances, and an impressive laser show in the evening. The festivities attracted crowds of people who came to see the show and celebrate the new national holiday. With a territory the size of Western Europe, a population of 16.5 million people, and rich reserves of natural resources, including natural gas and oil, Kazakhstan has become one of the five top oil-producers in the world and a political and economic leader in Central Asia. Steve LeVine, the U.S. policy analyst for *Foreign Policy*, considers Kazakhstan to be “the region’s most prosperous state, with the broadest middle class, the mildest autocrat and the most open approach to religion” compared to its neighbors.¹ According to the Human Development Index (HDI), a comparative measure of the economic well-being and social factors rated by the United Nations Development Program, Kazakhstan has considerably improved over the last decade, moving from 102nd place (out of 175 countries) to 73rd (out of 177) between 1996 and 2007.²

Capitalizing on its economic and natural resource wealth, Kazakhstan is currently investing in the modernization of its educational, medical, and social services, striving to move towards the standards of OECD countries. A nationwide education development program for 2005–2010 was instituted following a presidential address that set the goal of establishing an education system that would ensure efficient human capital development and the smooth integration of Kazakhstan into international-level education.³ One aspect of this new system is the establishment of a series of elite trilingual schools in which teachers and students are selected on a highly competitive basis.⁴ Named after the president, “Nazarbayev Intellectual Schools” are working in collaboration with a number of the world’s best-known educational institutions, including the University of Cambridge; the University of Pennsylvania; University College, London;

¹ <http://www.eurasianet.org/ussr/64701>. Accessed on December 20, 2011.

² OECD Report *Reviews of National Policies for Education. Kazakhstan, Kyrgyz Republic and Tajikistan 2009*.

³ From the government site <http://en.government.kz>.

⁴ http://www.edu.gov.kz/en/legislation/state_program_of_education_development_in_the_republic_of_kazakhstan.

Johns Hopkins University; the Institute of Education Measurement (CI-TO, Netherlands); and others, to create an elite, parallel system of high-achieving schools under the Prime Minister's Office rather than the Ministry of Education.

Meanwhile, the state has consistently overlooked the issues of social justice by focusing on these ambitious educational showcase projects. Although the inclusion of marginalized groups of children in mainstream educational institutions at all levels is essential to merging human rights and social justice with the current educational policy, inclusion is not a feature of the new elitist system. Paradoxically, a call for greater inclusion has been incorporated into a number of strategic policy documents, although there is not the same level of financial and political support for this aspect of the reforms.⁵ Article 30 of the constitution of Kazakhstan guarantees all children equal rights to education. In the first years after independence, Kazakhstan signed the Convention on the Rights of the Child (1994) and later committed to Education for All (EFA). It also signed UNICEF conventions guaranteeing equal access to education for all children and the UN Convention on the Rights of Persons with Disabilities (2008), which includes a right to education in inclusive settings.⁶

The Kazakh state's current ambitious goal of introducing inclusive education in 70 percent of state schools between 2011 and 2020 requires finding a viable solution to the multiple barriers in the current system.⁷ The current challenge for many governments in Central Asia is not only to respond to children's learning difficulties but also to reform schools so that they can accommodate a greater diversity of learners by adopting a child-centered approach to education. On the one hand, Kazakhstan is determined to follow the example of other developed countries: a combination of rights-based legislation, training, awareness campaigns, and reform of general education. On the other hand, some voices in the educational community warn of the need to create conditions for inclusion rather than forcing it on schools.

⁵ One of the target indicators in the State Program for Education Development for the Republic of Kazakhstan for 2011–2020 is to raise to 70 percent the share of schools that offer inclusive education. http://www.edu.gov.kz/en/legislation/state_program_of_education_development_in_the_republic_of_kazakhstan/ (accessed on December 10, 2011).

⁶ UN CRPD, Article 24.

⁷ http://www.edu.gov.kz/ru/zakonodatelstvo/gosudarstvennaja_programma_razvitiya_obrazovanija/.

Inclusion and social justice are areas where NGOs traditionally play an important role. They are sensitive to the needs of the target population and are often created by members of the civic society who are part of or have an intimate knowledge of the target population. NGOs can provide social assistance as well as participate in shaping state policies and providing feedback on government decisions. NGOs have experienced steady growth in the two decades since independence.⁸ Civil society in Kazakhstan is currently characterized by the gradual consolidation of the NGO sector, increased cooperation with the state, and the rise of organizations engaged in service provision and social development.⁹

In January 2006 the registration fee for NGOs was reduced, and tax privileges have greatly improved.¹⁰ In 2007 the government revoked the constitutional prohibition barring NGOs providing social services from receiving state funding.¹¹ These legislative steps have created favorable conditions for the further development of civic activism. Paradoxically, these reforms also created a way for progressive staff with sufficient power within state agencies to register daughter NGOs with access to grant funding and freedom from the bureaucracy and inertia that can hamstring reform. This case tells the stories of two children, many parents, and a web of NGOs working toward inclusive education in Kazakhstan.

Inclusive Education in Kazakhstan

Kazakhstan has recovered from the economic turmoil of the 1990s, and its GDP has been steadily increasing. This, however, has not translated into better education or social services; in fact, the proportion of GDP spent on education, social services, and health care has declined by almost half. Only recently has health care expenditure gone up slightly (from 2.2 percent to 2.5 percent).¹²

In 2002, Kazakh legislators developed and adopted the Law on Social and Medical-Pedagogical Correctional Support of Disabled Children, outlining a support system for children with special needs that included

⁸ Asian Development Bank. Overview of NGO/Civic Society. Kazakhstan. <http://www.adb.org/Documents/Reports/Civil-Society-Briefs/KAZ/CSB-KAZ.pdf>.

⁹ Ibid.

¹⁰ The fee for registering an NGO was reduced from 20,000 tenge (U.S. \$169) to 7,600 tenge (U.S. \$64).

¹¹ Ibid.

¹² The OECD Report (2009).

preventive measures, a system of education, and further training for children with disabilities. Putting this system into practice turned out to be a difficult task. UNICEF (2007) identified education of children with special needs as the primary challenge facing national education. Legacies of the past—segregation of education provision and of professionals, together with a medical discourse on disability—continue to be a barrier to linking inclusive education to general education reform.¹³

Not only has the legacy of the previous system thwarted more inclusive policies, but two additional debates—what is really “best for the child” and where to find money for child-centered programs that are perceived to be expensive¹⁴—have contributed to the persistence of barriers to inclusion. Many professionals continue to work in traditional ways and really do believe that they know best. School administrators worry that children with special needs will hold back the school ranking, which is based on students’ performance at the end of the ninth and 11th grades. The current competitive environment and the grades-based system of evaluating schools will have to accommodate inclusive classrooms:

While the need for standards is essential in a decentralized system, the attainments of those at the bottom of the league table are devalued when there is a drive for all pupils to achieve high standards, especially in systems that place a premium on achievement in comparison to others (UNICEF 2007: 67).

Thus the pressure on schools to show the highest possible ratings undermines the incentives for social justice. Many schools avoid admitting children with special needs, citing a lack of capacity to attend to the children’s needs. Such a view reinforces the traditionally held belief by many defectologists and other specialists that children with disabilities need the help of experts and do not belong in mainstream schools.

We interviewed two mainstream school directors about their experiences with including children with special needs to explore their concerns and examine barriers to inclusion from their perspective. The story presented was one of inadequate resources, little feeling of responsibility for inclu-

¹³ Only 32 percent of preschool children with special needs are currently receiving education, according to the Report of the Ministry of State Program for Education Development for 2011–2020.

¹⁴ This is the perception of school administrations and local education authorities. Compared to the overall costs of housing children in segregated boarding schools, inclusion is less expensive for the national budget. But it requires redistribution of funds between education and social welfare and an initial substantial initial investment in teacher training. In the long run, the operating costs of inclusive education are not higher.

sion, concern for school league table rankings, fear of innovation without express support from above, and distrust of the capacities of children to adapt in a mainstream class and of parents to assist them. One told us about “a stubborn parent” who insisted on having a child with a hearing problem join a regular classroom, which resulted in the child falling behind and feeling very uncomfortable. The school did not provide additional support. When asked about using the existing resources such as the social pedagogue or the psychologist to help the student, the director explained that both of these specialists were busy and had their own responsibilities.

The director’s unwillingness to consider a solution other than removing the student from the school illustrates the most common reaction to the parents’ insistence on the child’s rights. The director did not seek cooperation with the parent or see herself as responsible for educating the child, although she expressed some understanding of the student’s mother, who wanted to keep her daughter among “normal children.” Later, the director mentioned her own friend with a mildly autistic child, who was so uncomfortable with what she saw in special-education classes that she preferred to keep her child in a mainstream class as a “weak” but still “regular” student. The director had mixed feelings about inclusive education but did not want to apply it in her school:

It is good, in a way. But when I see the conditions created for them and the way they are educated in special institutions, that may be better for them. My experience is that these children [with special needs] must be taught in a different way.

School directors, who make decisions on whether to admit a child with special needs, usually have considerable experience in educational institutions and with the previous system of isolating children with special needs. They understand the need to create certain conditions for special-needs children in mainstream schools, but the benefits are not very clear to them. Directors who reluctantly take special-needs children tend to ignore their needs and provide unsupportive conditions. The child is integrated on paper but isolated in practice, and when the results are (predictably) disappointing, the directors use them to justify the previous system. Another school director interviewed did not want to take such risks or to make additional efforts and preferred to transfer children with special needs to private schools or offer them home schooling. She agreed, however, that if she had clear state regulations on what to do with such children, she would obey them. Even if she has little motivation to experiment, she would obey the rules set for everyone.

In the meantime, generations of children grow up missing their chance to exercise the right to education guaranteed them by the constitution. Sidelined into the system of correctional education or home schooling, they become further isolated from other children, fail to develop communication skills, and receive a substandard education, which closes an opportunity to get into the higher educational institutions. They are likely to form an invisible army of social welfare clients for the rest of their lives. Their families suffer from stigma and psychological pressure and lack the courage and resources to insist on the rights of their child. They may want to keep their child at home rather than send him or her to a specialized correctional school, but they fear that the system will backfire and hurt the child even more, so they agree to place the child into a correctional school against his or her will.¹⁵ The efforts of policy-makers remain futile, and the system of exclusion perpetuates itself.

“The A-Word”

In the professional slang of special educators, “the A-word” means “autism.” Among children with disabilities, children with autism are often the most marginalized, because their disorder is poorly understood. In the Soviet classification, autism was grouped with childhood schizophrenia.¹⁶ Moreover, if parents want to apply for disability benefits, the law requires that the child be removed from the family and placed in a psychiatric hospital for a month of assessment. This arrangement is currently debated by the top specialists: the president of the Association of Child Neurologists of Kazakhstan, Dr. Marzhan Lipesova, has been arguing for the need to refer autistic children to neurologists rather than psychiatrists, but the decision is still pending.¹⁷ Dr. Korlan Sadukasova, the chief child psychia-

¹⁵ Personal interview with a mother of a child with special needs.

¹⁶ People with classical autism show three types of symptoms: impaired social interaction, problems with verbal and nonverbal communication, and unusual or severely limited activities and interests. Isolated in worlds of their own, they appear indifferent and unable to form emotional bonds with others. They experience difficulties in understanding other people’s thoughts, feelings, and needs. The American Academy of Child and Adolescent Psychiatry outlines the difference between schizophrenia, a mental illness that is rare in childhood, and autism, which is a developmental disorder usually identified by the time a child reaches 30 months. http://aacap.org/cs/root/facts_for_families/the_child_with_autism and <http://aacap.org/page.ww?name=Schizophrenia+in+Children§ion=Facts+for+Families> (accessed April 2012).

¹⁷ Personal interview on September 18, 2011.

trist of the Ministry of Health of Kazakhstan, recently suggested after a presentation by Ashyk Alem that the current law has to be changed: the specialists and officials agree that it is against the interests of the child to be removed from his or her family for a lengthy psychiatric evaluation.

The number of children diagnosed with autism in Kazakhstan has been growing steadily, but official figures may still underestimate its incidence. The latest statistics show that there is one autistic child for every 10,000 children, which is few compared to one in 200 children in the United States or one in 80 in Great Britain.¹⁸ The low numbers recorded for autism in Kazakhstan may be related to the lack of a good system of diagnostics and concerns about the consequences of diagnosis outlined above. In May 2010, Mahmetkali Sarybekov, the vice minister of education and science, issued an order instructing the ministry and the National Center of Correctional Education to develop recommendations for referring children with autism to educational institutions. The order laid the foundations for including autistic children in mainstream schools.

Having an Autistic Child in Kazakhstan: State Services

For many parents in Kazakhstan, their odyssey through the labyrinth of services and assessments begins with one of the 56 regional or city Psychological-Medical-Pedagogical Commissions. Children with special needs in Almaty have to be evaluated for referral to education services in a special correctional institution or a general education school by the city PMPC before they start school. Its specialists belong to the old Soviet tradition that supports medicalization and segregation of children with disabilities, and conflicts between specialists and parents are frequent. Parents complain that the specialists of the city PMPC spend too little time with the children, hastily administer some outdated tests, do not give them time to adapt to new people, and rush to declare them “retarded.” The opinion of the parents is not taken into consideration.

Although the head of the city PMPC assured us that the evaluation had only an advisory status, this organization has real power over the child’s educational trajectory. The PMPC often refuses to refer children to regular classrooms, even if parents insist on inclusive education. While the PMPC

¹⁸ The statistics are taken from the interview with the leading specialists of ARIS (September 2011) and from the website Kazakhstan Today <http://www.kt.kz/?lang=rus&uin=1133169246&chapter=1153513230> (accessed February 2, 2012).

management and staff were dedicated to their work, they were trained under the old system, and they believe that specialists know more than parents, whose vision of the child is distorted by love and insufficient knowledge. Parents who continued to insist on their views being heard were referred to as overambitious, and their desire to send the child to a regular school was seen as lacking an understanding of the child's difficulties. Very few parents knew that they could file a complaint and get a referral to the national PMPC to appeal the decision of the city PMPC. Instead, they either accepted the referral to special education or tried to arrange the child's placement into the mainstream school by negotiating informally with a school director.

Having a child assessed by the city PMPC is a step that many parents dread, and the contrast between the national PMPC and the city PMPC is stark. These organizations not only work according to a different set of principles but also represent different philosophies on inclusive education and what constitutes the best interests of the child. The national PMPC and its non-profit affiliates help the family and the child to attend mainstream institutions. The city PMPC sends children to correctional classes and, if they do not improve or adapt to general education standards within a certain period of time, to segregated correctional education institutions. All the residents of Almaty must be assessed by the city PMPC, and only disputed cases are referred to the far more progressive national commission. Some parents arrange visits to the national PMPC and its non-profit affiliates informally. This demonstrates that the system lacks internal consistency and is extremely difficult to navigate, because it depends on the whims of school administrators rather than consistent policies and professional development for government agencies.

Support for Children with Autism

The most advanced institution in Kazakhstan for children with developmental problems (including autism spectrum disorders) is the National Research Center for Correctional Education in Almaty (NRCCE). It was founded in 1992 and has become a leader in social adaptation and rehabilitation of children and adolescents with developmental difficulties. The NRCCE has been offering practical help for children and parents, as well as developing training and research methodologies for specialists, for the past two decades. It houses the national PMPC, which evaluates children with complex or disputable diagnoses referred to it by any of the 56 city or regional PMPCs in Kazakhstan.

In 1996 the NRCCE created a non-profit organization—the SATR (Social Adaptation and Professional Rehabilitation) Center—to expand the scope of its work and be able to apply for international funding. The coordinator of SATR projects explained:

A state institution is limited in what it can do, particularly with international organizations. That is why our staff works part-time at the state institution and part-time at the non-profit. Sometimes we get confused which capacity we are in at a particular moment—state or non-profit employees—but that does not matter.

The SATR Center has been nationally recognized and has received an impressive number of national and international prizes for management and efficiency.¹⁹ In 2010 the NRCCE created another non-profit—ARIS (Adaptation, Rehabilitation, Integration and Socialization)—to apply for grants focused on upgrading the skills of regional specialists. These organizations collaborate with the state on improving the state system of services for children with disabilities and addressing problems such as the inefficiency of early diagnostics and intervention. Where state services fail to provide sufficient support for the child and the family due to limited funding and long waiting lists for services, a non-profit organization may step in. The professional expertise of the NRCCE specialists is spread through the work of the SATR and ARIS and creates professional networks throughout the country that are more flexible than the government agencies that spawned them. They can also apply for grant funding when the state budget is insufficient.

Every preschool child diagnosed with a developmental problem by the municipal PMPC is put on a waiting list and, when his or her turn comes, gets free correctional classes at one of the speech therapy offices (*kabinety korrektsii*) located around the city. There are long waiting lists for these services. Almaty, a city of 1.5 million people, has only four district speech therapy offices. Furthermore, even services that are set up for children with autism do not take account of their needs. One of the district speech offices that we visited was housed in a secondary school. While this location was convenient for students with speech problems from this school, the high level of noise during the breaks and the loud ringing of the bell made visits to these offices traumatic for children with autism.

The classes offered by speech therapy offices are twice a week for three months. All in all, it amounts to only 24 training sessions a year.

¹⁹ Information is from the center's Web site: SATR <http://www.satr.kz/about.php> (accessed on December 10, 2011).

Sometimes the child gets an opportunity to return and repeat the classes a few years later, but this is not a widespread practice because the state resources are very limited and the demand outpaces the supply. After a child has received the 24 state-funded sessions, parents are left on their own. It is impossible for children to retain the skills acquired during these three months unless the parents take over or hire private specialists.

The NRCCE specialists who set up SATR/ARIS have attempted to break this vicious circle by offering free extended services for children and families. Ms. Baglan Khalyanova, the coordinator, explained, “We offer free services for autistic children for one full year. Because how much can the municipal system do? And there are so many city children who need them right now!” All the specialists agree that parents play a crucial role in the child’s success. SATR and ARIS also target preschool children from low-income families in Almaty and offer advanced training for parents. Unsurprisingly, the mothers that founded Ashyk Alem came from the dedicated parents who took their children to SATR classes for several years and attended all the parent training sessions.

Ms. Khalyanova explained to us that combining the efforts of parents and specialists is crucial for success. She said, “It is the parents who have to insist on the rights of their children—from the government and from the teachers. We have much less power. Parents are the children’s legal representatives, and we need their initiative very much.” Specialists and parents needed to unite to improve the system overall. The SATR brought speakers from abroad—Maria Kominski and Olga Holland—who shared their experiences having a child with autism. The speakers inspired the three mothers with autistic children to set up a parent organization and were able to give good advice. After a period of hesitation, several mothers formed an informal group in 2009 and registered an organization in mid-July 2010. This is how the public foundation (*obschestvennyi fond*) Ashyk Alem came into being.

Ashyk Alem: From the Early Days until Today

The efforts of the mothers who founded the parent organization Ashyk Alem show what can be achieved. They not only managed to overcome the systemic barriers to educating their own children but also blazed the trail for other children pursuing paths within the mainstream education system, proving that inclusion is possible. These parents have invested time and money to overcome seemingly insurmountable obstacles. This would not have been possible without the support of progressive educa-

tion and health care specialists, who recognized the need to reform the existing system. The authors of this case study argue that parents are uniquely equipped both with knowledge and a very personal understanding of the problem to advocate for the rights of their children. In fact, our examples illustrate a simple idea: little is impossible for a dedicated parent; nothing is impossible for parents who are united.

From the start Ashyk Alem has sought to support children diagnosed with autism and other developmental problems as well as their families. In particular, it seeks to contribute to the improvement of the government program on early diagnostics and intervention and to collaborate on training state and NGO specialists and raising public awareness about autism. The founders want to help families deal with the stress following the diagnosis and help them make adjustments in their family life to accommodate the child's needs. Finally, they want to advocate for the equal rights for children to have access to medical, social, and educational services.

Currently, the organization is housed in the business office of one of the founders. The staff consists of the three founders, all mothers of children with autism—Ms. Arkharova (president), Ms. Sultanalieva (vice president), and Zhannat Karatai (vice president). There are occasional student-volunteers who help during some events; Ms. Sultanalieva trains and advises them on ways of developing leadership skills. The bulk of the work, however, is distributed among the founders according to their availability and skills. Ms. Arkharova does accounting and financial reports. Ms. Sultanalieva deals with collaboration with public, government, and international organizations and relations with sponsors. Ms. Arkharova and Ms. Sultanalieva prepare grant applications for projects and write reports; this represents a huge part of the activity of the organization. Ms. Karatai, a mother of four, deals with public relations, organizes fairs and exhibitions, and coordinates the activities of the parents' club. This work requires a significant time investment, and the three mothers maintain very busy schedules. As much as they want their own children to succeed in life, they are working hard to improve the existing system of services for all children and make it more modern, efficient, and accessible.

Conceiving the Organization

All NGOs are started by individuals or groups who want to advocate a certain course. Ashyk Alem originated from Ms. Arkharova's ideas about an NGO and the assistance provided by SATR specialists who tried to motivate the parents to unite. SATR realized the importance of having

allies in society and building coalitions in order to strengthen its own efficiency. SATR specialists kept telling the parents that they should demand better services for their children and explained that the authorities would not listen to them unless they united and created an organization. SATR invited parents from other countries who had children with autism to come to Kazakhstan, and they explained how they managed to defend their children's rights when they united. Ms. Komenski from Germany made a great impression on the parents with her message, "Everywhere in the world, parents are the driving force for defending the rights of their children. Nowhere will the state grant them without struggle." Ms. Arkharova was among the 20 parents who gathered on that day to listen to the speaker. She had been thinking about starting an NGO for over a year, but she felt she could not achieve anything on her own. Ms. Komenski's talk was a catalyst; Ms. Arkharova discussed the idea of starting an organization with Ms. Sultanalieva and others. Ms. Sultanalieva, who had known Ms. Arkharova for some time, hesitated before jumping into such a serious matter, but she felt that someone had to come to help:

Many parents gathered on that day, about 20, I think. But they all have many problems. I saw that Aliya did not have enough support. I have always dreamed of organizing a rehabilitation center for autistic children, because there were neither trained specialists nor adequate premises... I had a dream of having a diagnostic department, correction groups, physical exercise section, a hippodrome. And, if possible, even more: to be able to take children to Egypt, Turkey, or Ukraine for dolphin therapy. I really wanted to have younger children in it—under two years old! I wanted to offer each child high-quality assistance on a regular basis—not two 30-minute training sessions per week. To test different methodologies—I already knew that there were so many! To cooperate with kindergartens and educational institutions so that we could send children there while they get support from our speech therapists, psychologists, and special-education teachers.

It is not by chance that her dreams and the decision to support Ms. Arkharova appear together in this quote. These dreams would have remained fantasies had she not decided on that day that she would join Ms. Arkharova. Ms. Sultanalieva says that she always knew that starting an organization was a serious responsibility and a huge pressure on her time, which was already divided between her family and her business.

Initially, I did not want to take on much responsibility. I have very little spare time. Family and work take up most of my time. I said I would help, but I didn't want to be a co-founder. But I knew that it would all remain up in the air as usual. And I agreed.

Ms. Sultanalieva was not the only one who just wanted to help but not to commit—this was a common reaction among the parents. But she knew

that someone had to act, so she supported Ms. Arkharova and so did Ms. Karatai, who harbored similar doubts.

The SATR specialists welcomed their decision to set up a parent organization. Ms. Khalyanova said that they had known the three founders and had a lot of respect for them:

Dilara has worked on this problem for many years: her child was diagnosed when he was two. And since then she has been constantly working on educating herself and trying to help the child. She has read a lot. So did Zhannat and Aliya. They had visited Nikolskaya [an autism specialist from Moscow] with our psychologist. They were the first parents who responded to our efforts to unite parents.

For several months the three mothers worked together to develop the goals and strategy for their organization. In July 2010 they registered Ashyk Alem as an organization with the goal of supporting families raising an autistic child. They also planned activities to help reform the existing system of services by offering service providers ideas about the needs of the families together with suggestions for improving current services. The scope of the activities would include families, special-education teachers, journalists, civic society organizations, legislators, and policy-makers.

The Early Activities of Ashyk Alem

The scope of activities of Ashyk Alem in the first two years (2010–2011) is impressive. The new NGO participated in national roundtables and policy discussions as well as international conferences on autism. Advocacy activities included sending formal inquiries to Parliament, holding press conferences, and appearing on talk shows. All of this was accomplished alongside fundraising activities, training for other parents, and joining a regional initiative on autism in Central Asia.²⁰

Ashyk Alem conducted a survey of the state services for children with autism and produced a report²¹ that was very critical and outlined the state of affairs and the problems of the system through the eyes of its users—parents and children. Ms. Arkharova, the president of Ashyk Alem, pre-

²⁰ The Central Asian Autism Network (CAAN) was established in October 2011 by the parents' organizations of Kazakhstan, Kyrgyzstan, and Tajikistan by signing a memorandum of understanding. The mission of this network is consolidation of the parents' efforts through capacity-building, cooperation with authorities, and raising awareness about autism.

²¹ "Parent Evaluation of the Situation of Service Provision for Children and Teenagers with Autism in Kazakhstan" (unpublished report of Ashyk Alem).

sented the report to the leading specialist of the Ministry of Education. While seeking feedback on the quality of their services is not new for businesses, state institutions have little experience with such evaluations, and this had a powerful effect on the participants. The report sent a clear message that parents were prepared to speak to authorities and fight for the rights of their children.

Ashyk Alem followed this with a letter to Prime Minister Massimov requesting national statistics on autism and the list of services available to autistic children. Though the response disappointed the mothers—it was formal and outlined methodologies and services that mostly existed only on paper—a consequence of the letter was that Parliament and the prime minister were informed about the existence of autism. Unlike many grassroots parent organizations, the founders of Ashyk Alem not only chose to support the parents raising autistic children through their activities but also spoke on their behalf. Another round table in May 2011 discussed the gaps in services for rehabilitation and socialization. The lack of coordination among various departments and the three ministries involved (the health ministry, education ministry, and labor ministry), they explained, came from the lack of provisions stipulating the division of responsibilities and institutional orders on addressing specific problems of people with autism. The meeting concluded with the drafting of a resolution to consolidate the efforts of state, private, and non-profit agencies and coordinate services more efficiently.

The founders of Ashyk Alem have also focused on raising awareness about autism in the wider community. In November 2010 they organized a press conference attended by specialists and organizations willing to support them to build relations with journalists writing on social issues. This resulted in coverage from several publications informing the society about autism. This was followed by a charity fair at Haileybury Almaty, the first British private school in Kazakhstan. The charity fair allowed the new organization to collect funds and start a Web page, www.autism.kz, to share information about autism and intervention methods and details of forthcoming events. The mothers of Ashyk Alem also approached state authorities to ask for help in spreading information about autism. They received unexpected support and funding from the municipality to put banners in some streets for World Autism Awareness Day on April 2.

It is clear from the activities described above that the founders are professional women with social capital who are capable of skillfully transferring efficient business practices into the non-profit sphere. They are also well-informed about research and practice on autism internationally and

are able to pull together a network of similar parents. They started by giving their organization maximum publicity. They used their supporters among health and education specialists to attract media interest in autism, informing the public, legislators, and government officials. They built connections with potential donors and networks of international parent organizations. They attracted key players to participate in a dialogue about the problems of parents and children with autism and united with specialists from state institutions who promoted systemic changes. As parents, they knew what other parents experienced and organized activities for them. The strategy of targeting all the key players in the field from the earliest days turned out to be effective for a non-profit organization.

The main focus of the organization, however, was working with parents, the everyday heroes, who bore the burden of pursuing their child's rehabilitation. The Parent Club of Ashyk Alem started in 2011 and conducted a series of lectures, trainings, and recreational activities within the framework of the project "We Are Together." Mothers and children made art with the guidance of a volunteer artist and took a trip together, and fathers played a game of soccer—all these activities helped the families get to know each other and create support networks. These were the activities that were fondly remembered by the mothers who participated in a focus group about the role of a parent organization. They mentioned that it gave them a sense of togetherness and a chance to get out of the daily routines and do something creative.

The founders organized events for the other parents, who participated but did not commit to more active involvement. Uniting parents for civic activism in a country with no previous history of it is not an easy process. It also shows the huge step made by the three mothers who started the organization. The new organization already seems successful enough that its founders can take pride in what they have accomplished. But it occupies only a part of their lives. They are also wives and mothers and need to deal with the challenges of daily living. School is a major concern—keeping an autistic child in a mainstream school is a huge, time-consuming project. The next section examines the efforts of two parents determined to educate their autistic children in mainstream education. Their examples prove that inclusive education is achievable but requires close coordination between teachers and parents. The educational trajectories of two autistic children below reveal the barriers that have to be overcome if a child with autism attends a mainstream school.

Educational Trajectories of Two Students with Autism

Case 1: Kasym, 13 Years Old, Mainstream School in Almaty

There is no typical case in autism. Kasym's case is offered more as an illustration of the possibilities. As a child, Kasym was misdiagnosed several times by specialists. Before he was diagnosed with autism, he was declared deaf because he did not react to human speech. His mother says he is living proof that renowned specialists were wrong about him on four different occasions. Experts in Moscow told his parents that he would never talk. He is now in the fifth grade of a mainstream school. He talks and even recites poems in class. Kasym's parents were told that he could not participate in physical education classes because he would not follow directions, so he was removed from the school physical education classes. His mother took him to swimming lessons at the local swimming pool where, with the help of a friendly coach, Kasym now wins swimming competitions. Specialists insisted that Kasym would never be able to fly in airplanes, but his parents refused to give up. They worked with the boy, and now he travels all over the world with them. He does not enjoy long-distance flights, but he can cope.

Working to overcome all these difficulties was not easy, but his parents are justifiably proud of his success. However, the biggest success is that Kasym is attending a mainstream school. Since he could not speak until he was five, he was nine by the time he started school. His parents sent him to a private school hoping that the conditions would be better, with smaller classes and more attentive teachers. But they learned that teachers needed some training about how to work with children such as Kasym. Children with autism have little understanding of social rules: they have little sense about the proper codes of behavior, "right" and "wrong," and are often seen as undisciplined and spoiled. They may copy other children's misbehavior. Kasym may have seen a boy playfully lifting a girl's skirt; he did the same to his teacher. A terrible conflict ensued, resulting in the teacher quitting her job and Kasym being expelled from the school.

Kasym and his family needed a teacher who could understand him. The second time, they were lucky. His father had a conversation with the director of the neighborhood school and promised that the boy would receive additional support from private teachers; all he needed was socialization. The director understood and Kasym was placed in the hands of the best primary school teacher. She had no knowledge about children with

special needs, but she loved children and had a great intuition. A week before Kasym came, she started preparing the class for his arrival:

I explained to the children that this was a very special honor: they were allowed to have a very special child in their class. I said it was a great responsibility that the school granted them, and nobody else was trusted with this boy. I explained to the children that if he did not know something they knew, he would surely know other things that they didn't.

She showed the class Kasym's figurines—he had a gift for making things from modeling clay—and they made a big impression. This teacher created a welcoming and accepting atmosphere for the appearance of a child with behavioral problems. The class unanimously accepted Kasym from the first day. Children, especially the girls, took care of him with motherly feelings, and the boys protected him from conflict situations with other students who saw that he was “different.” Everyone understood that he had his peculiarities, but they were accepted.

Kasym managed to maintain average or slightly below-average marks. Home tutors repeated the classroom material for him (it had to be very close to what was taught), and he progressed. His class teacher decided, based on her intuition, that he should not be taught a special “reduced” curriculum—he should be required to learn like others. Even his mother did not see how that could be possible, but the teacher insisted. The largest breakthrough for Kasym (and his parents) was that he learned multiplication: his parents were convinced that he would never reach that level. But his teacher believed in his potential:

I said: “He will advance; he must feel that he is like everyone else. Even if he is getting only threes [satisfactory marks] now. But he sometimes gets fours [good] and fives [excellent]. He is smart and tried to elicit my compassion, manipulating me to give him higher marks. So he said of himself: “I am a strange boy. Please give me a five.” But he gradually started developing. And if he got a real four and occasionally a real five, I would always discuss his mark with the students: “Kasym deserves a four today—what do you think?” And he was so happy and proud. We even managed to persuade him to sit in the front desk—at the beginning he would only sit at the back. But he got used to being in the front.

Kasym's achievements, though they required enormous efforts from his parents, tutors, and teachers, are still astonishing. He managed to overcome the fear of coming to the blackboard and facing the class; he learned multiplication and division and progressed more than he would have if he attended a correctional school and followed a special program. Kasym's

teacher later attended training for teachers and parents organized by Ashyk Alem and ARIS. She realized that other teachers in the audience did not believe that inclusive education for children with autism was possible. She said she did not believe it herself before she had Kasym in her class:

It was very difficult for other teachers to believe that these children can be taught together with regular students. I didn't believe it myself at first. But when I started getting the results from Kasym, I realized that it was possible and that this boy could learn like everyone else.

Her experience contrasts sharply with the position of the city PMPC and some of the school directors that we interviewed. In their minds, parents who want to place their children in mainstream schools are pursuing unrealistic ambitions, because they do not want to recognize that their child has a “deficiency,” and thus they ruin the child’s educational opportunities. This position originates from the Soviet deficit-based discourse on disability, believing that only specialists know what is best for the child and forgetting that all knowledge is constructed in a specific socio-historical framework. The negative influence of the past is manifested when parents and children are denied an opportunity to explore the child’s limits. Kasym’s parents, who had collected enough proof that specialists can be wrong, were determined to give their child a chance to succeed. Because they managed to get informal support from the school director, they had a chance to demonstrate that—provided there is appropriate support—the results of inclusive education can surprise everyone. They contradict the educational trajectory determined by the Soviet-trained defec-tologists, who limit the opportunities for children with special needs while thinking that they are helping them.

Kasym’s case also highlights the two most important figures for inclusive education to succeed: the teacher and the parent. The class teacher from Kasym’s private school could not adapt to his misbehavior; she expected him to act like an average disciplined student, but he could not. His second teacher found a way to create a classroom atmosphere that encouraged Kasym to follow positive models of behavior and patiently explained social norms to him. The role of Kasym’s parents was crucial: they provided all the necessary after-school help, supported his teacher in understanding children with special needs, and collaborated with her on daily basis.

However, this situation changed abruptly after the first four years, when Kasym started middle school and had different teachers for each subject. Within the first few weeks, the social pedagogue called a meeting

between Kasym's mother and his teachers due to complaints about the boy's behavior. According to her own observations, Kasym refused to follow teachers' instructions. We asked for and were granted permission to attend the meeting as observers.

The teachers who came had no knowledge about Kasym's autism and no experience with children with special needs. One of the teachers had worked in schools for 30 years but had never had children with special needs in her class. The reaction of the teachers at the beginning of the meeting was unanimous and overwhelmingly negative: they expressed their discontent with Kasym's lack of attention and suggested that he leave the school. Nobody had any interest in getting through to him. Although Kasym's mother mentioned that she was there in two capacities—as a parent and as a vice-president of a parent organization, Ashyk Alem—she was close to tears.

She tried to remain calm and started explaining Kasym's case. She stressed that his presence would not require additional effort from his teachers and promised that he would not fall behind because he had very strong after-school support. The atmosphere of the meeting gradually began to change. Teachers started asking her questions. The music teacher asked how to deal with his behavior: he sat through her class repeating, "I hate music." The mother said she should reprimand him. The literature teacher, who seemed to belong to the "old guard" now approaching retirement, was the most vocal in expressing her discontent with Kasym's noncompliance. Kasym's mother pacified her with promises to come to class and help to keep him focused. They also scheduled a separate meeting to get information about all the requirements for the class.

Kasym's English teacher, the youngest of the group, showed the most compassion for Kasym's case. She was willing to learn about his special needs and keep him in class, even though his behavior distracted other students. Finally, the social pedagogue, a young, kind, and intelligent woman, switched sides, from suggesting that Kasym should leave to getting interested in learning more about autism and promising to support him. All in all, the meeting ended well but still demonstrated the seismic shifts in educational philosophy necessary to make inclusive education the norm in Kazakhstan.

Although we initially expected that the teachers would be interested in learning about Kasym's autism and that his mother would inform them how to deal with a child with special needs in the classroom, the reality was different. What worked best was the promise that Kasym would not be a burden to them. After the meeting, Kasym's mother explained to me that she

may consider hiring some of the teachers as tutors to ensure Kasym's progress. However, a middle school with many different teachers is a serious challenge for a child with autism, and that has to be addressed.

The interview with the newly appointed director of Kasym's school showed that even school administrators with a generally positive attitude toward inclusive education have little understanding of how it can work. The director said that she had heard about some experiments at Russian and Kazakh schools to socialize children with special needs. She had some experience of working at a school attended by a girl with cerebral palsy. She had heard about an experiment on inclusive education at three experimental schools in Almaty, but she did not support it: "These schools have to admit these children whether they like it or not. Everything in our education these days is pushed to match the international level." But she valued the role of the parents and acknowledged their right to demand equal rights for their children from the city and regional education managers:

The director is always caught between a rock and a hard place. You can lose all your humanism in this position. But parents can have a voice. They can demand from me that I take their child, and they can complain. Then I will be summoned by my bosses, and I will say: "But I have no ramp." It is difficult for me to demand a ramp from my superiors, but I can inform them about the children's needs in this way. Or, if I had normative documents, I could use them to promote this cause.

Some school directors are willing to admit children with special needs based on their own judgment. However, most specify that the children with special needs must have a "normal" level of intellectual development. The new director of Kasym's school agreed that children with "intact intellect" (*so sokhranim intellektom*) could study in a regular classroom, but she could not imagine including children with autism or other difficulties until the state found funds for a personal assistant or a speech pathologist. Without additional support, children like Kasym would not be able to study in her school, she said. Kasym's success was his parents' achievement and not the school's.

Case 2: Tore, Eight Years Old, Private Primary School

Tore was a quiet child. His grandmother was the first to notice and tell his mother that there was something strange about him: he did not cry when his mother left, nor did he rejoice when she was back. At other times he cried a great deal and had convulsions. He was taken for consultation to four different doctors and several private practitioners, who charged exor-

bitant fees. At the age of three and a half, Tore still did not respond to his name or listen to anyone speaking. Hoping that Tore would open up with other children, his parents took him to a private kindergarten. He sat alone in the corner all day, and the staff told the mother that he was a very easy-to-handle child. The city PMPC diagnosed him with delays in intellectual development, and though his mother insisted on getting a referral to a speech therapy kindergarten, she was not listened to. The specialists at the city PMPC insisted that the child was asocial and the specialists at the kindergarten would not have time to work with him individually. The boy was referred to a district speech therapy office (*cabinet korreksii*) to work with a psychologist and a speech therapist.

Tore's diagnosis was made by the psychologist at the speech therapy office, who said he might have autism. She told his mother to read about it and decide if the symptoms fit the description. After that, there was no doubt. Tore's mother said she cried for a month, but finally there was clarity. Reading everything they could find about autism on the Internet, Tore's parents found a wonderful Web resource in Russian, created by a woman from Canada, called "Autism—a Road to Healing." They took the child to various therapies, swimming lessons, and karate lessons with private coaches to develop his physical abilities, as well as to a drawing class and to two music teachers. They looked for people willing to work with a child with special needs and explained his difficulties to them. They even took Tore to dolphin therapy in St. Petersburg. The whole family tested different methods shared by parents with autistic children around the world. For instance, the whole family started a diet recommended for autistic children; though the father was somewhat skeptical, he did it too. After six months the boy said "mama" for the first time. She couldn't help crying.

Tore's parents worked hard on launching an intense intervention therapy to alleviate the boy's dysfunction. Tore had a private speech therapist and a private psychologist between the ages of three and a half and seven and a half. This allowed him to make considerable progress. When he was seven, he started at a private primary school called Intellect, which he is currently attending. His mother explained to the director²² and teachers the problems the child had and promised full support, but the school was not prepared to handle "unusual" children. He had behavioral problems and was hyperactive, so he was allowed to walk out of the classroom during

²² All the interviewed officials have been promised anonymity, so their names do not appear in this report.

the lesson. He would loudly express his indignation towards the teacher when not given good marks. Initially, this upset other children, who were taught to be disciplined and respectful, but the teacher explained to them that Tore “was very sensitive.” In his first year, he had a serious conflict with another child, and Tore’s parents took their son from school, though the school administration was determined to resolve the problem. The goal of their school, said the director during the interview, is to learn how to teach anyone:

Initially, we were not ready to handle children with special needs, but our leading teacher has a second higher-education degree as a psychologist. So it helped. Often parents do not want to tell us the truth about their child’s problems. They bring documents that don’t mention anything. But our school is small, our classes consist of 11, five, or sometimes even three or four children. We take everyone, and we are prepared to work with all students. We conduct entry tests only to understand what level of preparation the child already has, not to select children.

Tore’s mother was a great resource for the school, because she invited the teachers to training seminars organized by Ashyk Alem. All the teachers and other staff of the school attended these trainings, because in years to come, they expect to have more problematic children who fall out of the mainstream education. So the teachers want to acquire additional skills and knowledge in advance to be prepared to understand the needs of these children and the nuances of their behavior. The teachers meet on a weekly basis to share their instructional methods and discuss ways to keep the students interested in learning. They take psychological tests regularly to have a clearer picture of themselves, because it is stressful to work with students with behavioral problems. The philosophy of this school is to teach and love every child who comes to them. The director supports the teachers in developing their skill to become attuned to the children:

With time, there will be more and more children who need special attention. And we must be ready for it. We must read and keep ourselves informed. Parents of children with special needs are told: “Your child will pull our school back.” This is because these children require much more time. And we understand that when you have only 40 minutes and you need to explain a lot to a large class, the teachers cannot give enough attention to every child... We feel that we need to get training in special education to work with these children.

The director of the Intellect School was genuinely proud that the school has been able to uncover the unique qualities residing in all the children it admits, including children with autism, who often have unusual talents

and skills. Training, in this case, is a natural extension of the school's willingness to understand and address the child's needs in the best possible way. But the school's staff is aware that the small class sizes make this possible. The Intellect School is working on establishing co-operation with parents, especially those parents of regular students who are not happy to see their child side-by-side with children they see as engaging in "bad behavior." Teachers explain their position patiently and are very proud when they can win the parents over.

Tore's school life is not trouble-free. Children with autism are "different," and other children notice that difference. Teachers need to work with the class to ensure such children are accepted, and conflicts can still happen. Several boys ganged up on Tore and beat him up but denied it when teachers tried to investigate the conflict. The teachers were not sure whether Tore was imagining the incident or telling the truth, so his mother invited in a specialist from the speech therapy office, who explained that autistic children are unable to lie. The consultation of a specialist helped the teachers to establish the truth and resolve the conflict. The children have learned a lesson of tolerance and kindness due to the consistent efforts of Tore's mother and the teachers.

Tore's parents succeeded in placing him in a private school but in a regular classroom. The school was prepared to work with such a student, adapt to his needs, and help him overcome his problems and adapt to school life and other children. The school has already acquired considerable experience in dealing with children who are excluded from mainstream schools. Its director is genuinely proud of the staff's ability to find an approach to and uncover the uniqueness of every child, and she insists that nothing can be done by the school alone, without collaborating with the parents. Tore's mother played a crucial role, patiently working through difficult situations with the teachers and helping them to educate themselves about the diverse needs of their current and future students.

Two Schools—Two Approaches

The comparison of the two educational trajectories from these cases shows the presence of two radically different school philosophies. The majority of schools set the rules and require children to adapt to them, while a minority of schools help their students to overcome their problems and adapt their expectations to the needs of the child. Hyperactive children, children with learning difficulties and behavioral problems, who

cannot meet the mainstream school demands to sit still for lengthy periods of time and to keep their attention on the teacher are excluded from most schools. If their parents can afford it, there is the option of a private school, but not every private school is willing or able to offer such professional support as the Intellect School. The existence of this school is beneficial for students with special needs who attend and it demonstrates what can be achieved if a child with autism receives support from the educational institution.

Children with autism remain an enigma for many teachers and specialists. Dr. Lepesova, the chief child neurologist at the Ministry of Health, mentioned in her interview that there is much to learn about them: "Nobody likes children with autism, because very few people understand what to do with them." A similar opinion was expressed by a speech therapist who works with children with special needs: "Nobody likes working with children with autism, because you cannot receive a quick result. It is also difficult to define their intellectual development, because they don't want to communicate." The role of the parents raising a child with autism is challenging: they must become their child's ambassadors and build a bridge of understanding between their child and the surrounding world. They are the most important resource for the child, and they understand and support the current state efforts to adapt their child to the education system and help the child's socialization.

There are two versions of inclusive education reform promoted by the Kazakh policy-makers.²³ One direction of the reform is to create the opportunity for students with special needs to study in special classes within mainstream schools. This creates an environment where children with special needs can interact with other children, but it does not include them fully. The second direction of the reform is much more challenging: schools must include children with special needs in the regular classroom. This requires a change of philosophy on the part of the school by placing the child at the center and radically changing who adapts to whom and what criteria other than high test scores can be used to measure good outcomes.

If classes in mainstream schools are overcrowded and teachers have no time to pay attention to each child, everyone loses, and the student-centered approach will exist only on paper. What makes inclusive education so complex and yet so important is that it can contribute to making

²³ See the description of the state policy at the government education portal <http://www.edu.gov.kz/index.php?id=984&L=1> (accessed on February 20, 2012).

real change in mainstream education. It will require retraining teachers willing to adopt this new teaching philosophy and prepared to understand a variety of students and their problems. The educational trajectories of the two autistic children through a mainstream school and a private school show children's potential to develop far beyond the limits set for them by the correctional education specialists when these children are placed among peers. They benefit significantly from developing friendships and new behavior models, which becomes an important step for their future integration in society.

The success of inclusive education greatly depends on the efficient collaboration of parents and teachers. On the one hand, the role of Kasym's primary school teacher was crucial: she prepared the class for Kasym's arrival and made the children feel special for being chosen for that responsibility. On the other hand, Kasym's progress in the mainstream school program was also due to his parents having the determination and the financial means to hire tutors. Children with special needs who receive appropriate support can succeed in mainstream school education. In addition to changing the way that the classroom works, support services must also be developed so that a child's access to inclusive education will not be based on his parents' ability to pay for it.

Tore has a different trajectory through the educational system. He attends a private primary school, but his parents hope he will move to a mainstream school in a few years. They want him to learn to function among other students, and they are prepared to support him further. His mother knows that she will have to prepare the teachers when he moves to a mainstream school, so that they prepare the students to accept him. But she considers it worth all the effort.

Over time, Ashyk Alem will be able to establish closer collaboration with specific schools that will specialize in admitting children with autism and will keep working with mainstream-school teachers, explaining what the child needs and inviting them to lectures and trainings. Another aspect of their work involves educating society about autism, using media and debunking the old belief that isolation is in the child's best interests. On the contrary, every successful story and every child that has adapted to a mainstream school helps them argue their case: education should be for all children.

Conclusion

This case study looked at a new phenomenon in Kazakh society—parent activism. It focused on Ashyk Alem, a new organization of parents. The organization has demonstrated considerable potential to become one of the leading NGOs in Kazakhstan supporting and defending the rights of children with autism. It contributes to the advancement of the system of services: diagnostics and early intervention, health services, social support of the family, and access to education, all of which contribute to the inclusion of children into society. Looking at the components of Ashyk Alem's success, we see a combination of four broad factors.

First, the mothers belong to a new type of parent that has emerged in the post-communist era. These are middle-class parents with advanced professional degrees, working in business or other fields and capable of transferring managerial skills and practices into non-profit management. The founders of Ashyk Alem can write successful grant applications and submit detailed budgets. They can access modern sources of information and learn from them, and they actively educate themselves on the most recent research about autism. Specialists recognize that parents can be better informed on the narrow topic that is relevant to their specific child's problems.

These parents have access to private consultants, who often belong to the same social networks, and international experts as well as other parent organizations around the world. Since the national system of professional training collapsed after the fall of communism, these parents can be a valuable resource of information and training for the local specialists. They share information with them and write grants to invite professional trainers. They have even taken local specialists on trips abroad, when the child was evaluated, to get a second opinion. They understand their rights as citizens and demand that the services their children need be established within the country, at a sufficiently high standard.

The second factor that has contributed to the success of Ashyk Alem is that the mothers have always received support from their husbands. Despite the cultural tradition that the women of the household should be the ones to focus on the family and their own children, the fathers in these families participate in the child's education and recreational activities, take interest in the methodologies that specialists use, and can debate their efficiency. They agree that the work performed by their wives is carried out in the name of the child and for the future of the child, because no matter how favorable the conditions are inside the family, the child needs to be connected to the wider world and accepted there.

The third factor of success lies in keeping a broad view of the system while addressing specific problems of children with autism. The team of three people organized press conferences and round tables with leading national specialists alongside activities for families and children. The founders stepped out of their individual situations and became the voice of parents of children with autism. They have pointed to the systemic problems in health care, education, and social services, criticizing their lack of efficiency and outdated practices. They have addressed problems at the bottom of the system and at the top. They have challenged the old regulations that required families to place their child at a psychiatric hospital for a month-long evaluation if the family wanted to apply for social support. They aim to defend the rights of their own children while alerting the policy-makers to the deficiencies of the system.

Finally, the founders of Ashyk Alem would not be able to succeed without the respect and support of some specialists within the state system who wanted to develop new ways of working. Creating coalitions between the state, non-state agencies, and parent organizations gave these specialists additional leverage to promote change. But change is slow, and there is still much work to do. As highlighted above, few mainstream schools are ready for inclusion, and many professionals are resistant to new ways of working, because of their longstanding professional identities and perceptions of their roles. Change will take time and will require a substantial shift in the preparation of all the professionals who work with children with disabilities together with sustained professional development for those already in their positions. Nothing less than major shifts in attitudes and responses to disability and to the human rights of marginalized groups are required. But a start has been made, and parents in Kazakhstan have been instrumental in this process of reform, as they have been in other parts of the world. The initial support of the Soros Foundation, which gave the mothers a travel grant to visit a congress on autism abroad, allowed them to become part of the international movement of parents. The organization has also offered support to the state system in such crucial areas as organizing training for teachers and specialists and giving the state feedback on the services for families of children with autism.

Although these are the early days of parental activism, parents have gradually realized their rights and have transformed from passive recipients of state services into active advocates of their children's rights. They have built networks such as CAAN (Central Asian Autism Network), have strengthened their voice, and have become more empowered. Recognition by the expert community helps the parents to make their voice heard: they make

presentations at professional meetings and contribute to a dialogue that was previously open only to policy-makers. This model of collaboration between the state, businesses, and non-profits is still new for Kazakhstan but is bringing more actors to the discussion table and promises to be productive.

On the national level, Kazakhstan is currently promoting two very different versions of educational reform. One is based on the creation of a series of new, elite, highly selective schools, the Nazarbayev Intellectual Schools, hardly a solid foundation for the development of inclusion. The other is informed by international standards of inclusive education and social justice, with the aim of making 70 percent of schools inclusive by 2020. This latter vision creates further grounds for cooperation with state institutions, but it will be within a contested policy space. Other countries, too, have educational policies that contain seeming contradictions, for example, in terms of elitism versus equity, universal access versus selection, or centralization versus localism. In many parts of the world, the educational policy arena has become more politicized, but it is within these contested policies that spaces are created where parents can have great influence. In Kazakhstan, as in many other countries, power and influence is shifting from professionals, who “know what’s in the best interests of the child,” to parents, who “know the child best.” When working together, parents and professionals can create powerful coalitions to improve educational provision and services for children.

An unexpected finding during this case study was the fact that the specialist from a state organization, the NRCCE, created the conditions that made Ashyk Alem possible and encouraged parents to unite and become active. Future developments will depend on professionals and parents continuing to work together. With the support of progressive professionals, often working to reform the system from the inside and outside at the same time, the parents realized that the system of services for autistic children, even in the most developed countries, was created through the efforts of ordinary parents. Ashyk Alem has become a strong player in the field due to the profound understanding of autism and its efforts to raise awareness about it in the society.

Parents who have succeeded in keeping their children in mainstream schools have acquired valuable experiences to share with others. In the meantime, they keep working hard, hoping that other parents will join them or will start their own organizations. They want to send the message that parents making individual efforts on behalf of their own child can do only so much, but if parents unite they can achieve much more, especially when working with key professionals. Their own example is proof of that. On the road of including a child with special needs into society, every

small victory counts. They hope their organization will grow and that more families and children with special needs will have productive and happy lives in their country.

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List of interviews and focus groups

- 1) An interview with Ms. Khakimzhanova, the president of the Association of Social Workers, the Disabled and Volunteers, who has had long-term experience at the Ministry of Social Welfare;
- 2) An interview with the chief child neurologist of the Ministry of Health Care, Dr. Lepesova;
- 3) Interviews with Ms. Khalypova and A. Ersarina, employees of the leading research and practical support organizations for autism—the National Research Center for Correctional Education (NRCCE) and two non-profit organizations that branched from it—SATR (Social Adaptation and Professional Rehabilitation) for children and adolescents with developmental deficiencies and ARIS (Adaptation, Rehabilitation, Integration, and Socialization);
- 4) Two interviews at the city Psychological-Medical-Pedagogical Commission, an organization that evaluates the child's needs and dispatches him or her to an institution of correctional education (S. Kassimova);
- 5) A focus group with the team of about 10 psychologists and special-education teachers at a regional speech clinic (*cabinet korreksii*) in Almaty;
- 6) A focus group with parents of autistic children who attended the events organized by Ashyk Alem;
- 7) Two interviews with directors of mainstream schools who do not admit children with special needs;
- 8) Two interviews with school directors (one of a mainstream school and one of a private primary school) who admit children with special needs;
- 9) One interview of a social pedagogue following the meeting between the middle-school teachers of one of the autistic children and his mother;
- 10) Three interviews with the founders of Ashyk Alem.

Fools Rush In: A Path to Inclusive Education in Petropavlovsk, Kazakhstan

Nils J. Kauffman and Larisa Popova

“We are good people,” answered the director of School 13, Lidia Mikhailovna Maslova, when asked why she agreed to collaborate with Shamil Taufikovich Shakshakbaev to enroll 20 students with special needs in her school more than 10 years ago. What started out as an experiment is now a resource for the region and an example of the beginnings of inclusive education in Kazakhstan.

In 1999 Mr. Shakshakbaev proposed to the regional educational authorities the establishment of a rehabilitation center that would eventually be called the “State Experimental Center for Rehabilitation and Adaptation for Child Invalids with Limited Mobility” (hereinafter, the Center). This represented a significant break from traditional Soviet policy, which kept students with physical disabilities in their homes for homeschooling. Despite this tradition, the regional authorities realized that they should do more for children with physical disabilities. Once Mr. Shakshakbaev gained the support of the regional authorities, he set up a residential home and approached several schools before Ms. Maslova, the director of School 13, accepted his proposal to admit students with disabilities into her school.

What inspired this idea, no one knows, not even Mr. Shakshakbaev. Both Mr. Shakshakbaev and Ms. Maslova had personal experiences that raised their concerns about the opportunities available for children with limited mobility, but neither of them had any experience with inclusive education. Mr. Shakshakbaev had no experience teaching, but after losing both legs to an illness and reflecting on the state of other disabled people, he came to the conclusion that children with disabilities would benefit by attending a regular school with other children and that the Center would

be an important step in achieving this goal. For her part, Ms. Maslova had a daughter who had difficulty walking until an operation repaired her hips. She understood the barriers preventing non-ambulant children from attending school.

Now the faculty at School 13 and the staff of the Center collaborate to support the 20 children and young people who live at the Center and attend School 13. The Center has a staff that includes physical therapists, a speech therapist, and a psychologist. In addition, the Center has tutors who attend lessons at the school with the students and support them with their homework when they are back at the Center. However, School 13 does not have assigned special-education teachers or therapists, because it is not considered a “special school” where students with special needs would typically study.

This case study aims to shed light on the origins and the challenges of including students with disabilities in School 13. Inclusion is official national policy in Kazakhstan, and the government’s goal is for 70 percent of schools to be accepting students with special educational needs by 2020 (MOE 2010). Yet few schools in the country have taken concrete steps toward implementing this policy. The experience of School 13 provides insights into the process of including students with special educational needs in regular schools and may provide some lessons for schools elsewhere about the process of achieving greater inclusion.

Exploring the Case: Methods

The two authors each spent a total of 10 days in 2010 and 2011 conducting research for this case study. Dr. Nils Kauffman is an education consultant from the United States who has taught and researched in the former Soviet Union over the past 15 years. Larisa Popova is a former teacher who founded and now edits the education magazine *Otkrytaia Shkola* [Open School].

Ms. Popova first visited the school in the fall of 2010. She made her visit alone and wrote her observations in an article in her magazine (Popova 2010). Together both authors visited the school in the fall of 2011. For five days they observed classes and conducted interviews.

Research for this chapter relies on data generated using qualitative methods designed to clarify the dynamics and context of inclusion in School 13. During the visits to the school, we were able to carry out observations and conduct formal and informal interviews with the director, the assistant

director, teachers, parents, and students, who lived either at the Center or at home with their families. Formal interviews used semi-structured protocols, and informal discussions took place between classes or after observing lessons. Lessons were observed in a variety of subject areas and at both primary and secondary grade levels.

Table 1: List of Classes Observed

Grade	Subject
3	Math
4	Science
7	History
8	Life skills
9	English

Parents of students with and without special educational needs spoke with us, and we were also able to interview some graduates of School 13. In addition, we interviewed the director of the Center and visited the facility. To gain a national perspective on the issues of inclusion, we spoke with a university professor who focuses on the issue of special education and inclusion.

Although the school's faculty welcomed our visit, the short time frame of the site visits limited the range of data-collection opportunities. Students and teachers change during the academic year, and it is not possible to observe the full range of teaching and learning activities within two weeks. The presence of researchers, particularly a foreign researcher, changes the dynamics of a class. As a result, this case study is a snapshot of the life of School 13.

It would be impossible to maintain the anonymity of the directors of the school and the Center. We have used their real names in this chapter. For teachers and students, we have used only first names or referred only to the position of the individual.

Whenever possible, interviews and discussions were recorded and notes were taken. We could not record spontaneous discussions with teachers in between lessons. However, in these cases, we did take notes. After the field visit, Dr. Kauffman reviewed the interviews and selected portions for transcription.

Country Background

Kazakhstan is the largest of the Central Asian republics and, by land area, is the fifth-largest country in the world. The population of Kazakhstan is about 15.5 million, consisting of Kazakhs (63 percent) and Russians (24 percent), with as many as one hundred different ethnic groups making up the total. Russian and Kazakh are the most widely spoken languages, and about two-thirds of the population speaks the former (U.S. Department of State 2009). School 13 is a Russian-language school, in part because of its proximity to Russia. Both ethnic Kazakhs and Russians teach and study in the school.

Russian influence in the region dates back centuries. Beginning in the mid-18th century, the Russian Empire took over most of the Kazakh territory, and by 1860s nearly the entire territory was part of the Russian Empire. In 1920 the territory became an autonomous republic within the USSR, and in 1936 it became a Soviet republic. Kazakhstan became an independent country in 1991, with the dissolution of the USSR.

During the Soviet period, primary and secondary education was extensively developed in Kazakhstan. Enrollment and literacy were both nearly universal (Shagdar 2006). The literacy rate is still high at 98.4 percent (U.S. Department of State 2009). The Soviet school system consisted of 11 years, from Grade 1 to Grade 11. All teachers were expected to follow a very structured state-sponsored curriculum, which defined both the content to be taught and the methods for how it should be taught in great detail. Preschool was not considered part of school and was not as widespread as schooling; however, access increased through the 1980s. Soviet citizens had many opportunities to continue academic study or to prepare for a trade after finishing secondary school, but such opportunities were limited or nonexistent for students with disabilities. These students attended special schools or residential institutions for children with disabilities, or they studied at home with a visiting teacher for a limited number of hours each week.

Life for Kazakhstan after independence in 1991 was not easy; GDP declined by 50 percent following the dissolution of the USSR. The decline in revenue forced the new country to close down significant portions of the social welfare network built in the Soviet era. This was particularly hard on students in special-education institutions and kindergartens. But all schools suffered from a lack of funding, and access to kindergarten decreased significantly. In recent years income from natural resource extraction has strengthened the economy and increased funding for education (OECD 2009, Shagdar 2006).

As an independent country, Kazakhstan has ratified a number of international treaties and conventions concerning education and the rights of children (OECD 2009). These include the UN Convention on the Rights of the Child, the UN Convention of the Rights of Persons with Disabilities, and the Salamanca Statement and Framework for Action on Special Needs Education (OECD 2009). The rights and strategies outlined in these accords have been incorporated in national laws including the Constitution (Republic of Kazakhstan 1995), the Law on Education (MOE 2011), and the Law on Social and Medical-Pedagogical Correctional Support of Disabled Children (MOE 2002).

Significantly, these laws provide rights and a legal status for students with disabilities and represent a break from the Soviet past by promoting the participation of students with disabilities in the wider society. However, progress on implementing these laws and on developing inclusion has been slow (UNICEF 2007).

According to the laws in Kazakhstan, the rights and privileges granted to children with disabilities and their parents include the right to choose an educational establishment (special school or regular school), the right to free primary and secondary education, free medical care, free basic medical training, free social and medical correctional support, and some adaptive technology or equipment (MOE 2002, 2011; OECD 2009).

The table below shows the number of students with special needs attending the different types of facilities in Kazakhstan in 2010 (MOE 2010). By comparison, 2.5 million students attend regular schools.

Table 2: Type of Schooling for School-Aged Children with Disabilities

Type of Facility	Number of Students with Disabilities
Special schools	24,246
Special boarding schools	7,582
Regular school with support	3,925
Regular schools without support	26,623

Source: OECD, 2009

A variety of special schools are operating in Kazakhstan. Different types of schools cater for students segregated according to the category of their diagnosis. Boarding schools provide for some children with special needs who live far from the special day schools, which are typically located in larger population centers.

It is uncertain how many children with disabilities remain at home. Estimates collected by the OECD (2009) suggest the number may be as low as 12,500 or as high as 55,000. This homeschooling typically consists of a visit by a teacher for four to six hours for elementary-school-aged students and eight to 10 hours a week for high-school-aged students. This compares to 24 to 36 hours of instruction per week for students attending regular school (OECD 2009).

Despite the laws promoting inclusion, segregated education still exists in Kazakhstan. According to a UNICEF report, this takes place for several reasons:

Children with disabilities have largely not been mainstreamed in the public education system because of varying factors. First, because of low preschool enrolment rates, many children's special needs go undiagnosed or unnoticed until primary school. Second, there is a severe lack of services to address disabilities before or during schools [sic]; there are very few education professionals trained to work with children with disabilities, technology is not available to schools to support children with special needs, and medical services are not available for children with severe developmental problems. Lastly, there are no legislative systems to insist that special needs children be included in the public education system nor are there any regulatory processes to hold the system accountable. (UNICEF, undated, 2)

According to Zulfiya Movkebaeva (real name used with permission), a research specialist at the Abai National Pedagogical University, the challenges to inclusion do not lie in the education laws, but rather in their implementation. Parents have the right to choose a school for their children, and can choose a regular school. However, the school administration often refuses. Common excuses are that there is not enough room at the school or that it is too far away from the child's home (personal communication, October 20, 2011).

However, another fault, according to Ms. Movkebaeva, lies with the choices confronting the parents of special-needs students. Within the current structure of social services, children with special needs get many benefits such as free therapy and field trips, and at special schools, students are fed and clothed for free. If a student with special needs transfers to a regular school, and if there are no changes in the law, parents must pay for food, clothing, field trips, and therapy. It could be argued that parents who fear losing such benefits or cannot afford to provide these things for their children will keep their children in segregated education.

"They are afraid... all week the children do not bother them, the state feeds them, clothes them... They are not responsible for their children" (personal communication, October 20, 2011).

In order to overcome some of the structural and financial barriers to the development of inclusive schools, numerous organizations have worked to promote inclusion in Kazakhstan. They have provided services to students with disabilities as well as promoting inclusion. These organizations include Soros Foundation–Kazakhstan, USAID, and UNICEF. Although these organizations have had small-scale success, much more needs to be done to implement inclusion on a national scale (UNICEF 2007). Since Kazakhstan ratified the Convention on the Rights of Persons with Disabilities at the end of 2008, Article 24 could be used as a guide for evaluating current legislation and regulations in the systems of education, public health, and social protection to ensure that they are comprehensive, mutually reinforcing, and as supportive of inclusion as possible.

Independent of international organizations and in spite of the ways in which education policy is being enacted, School 13 has successfully implemented limited inclusion of children with physical disabilities. Instead of relying on external support, School 13 has succeeded as a result of individual actors working to provide educational and life opportunities to children with limited mobility.

School 13

School 13 is located on the outskirts of Petropavlovsk, a city of about 200,000 people and the administrative center of the northern region of Kazakhstan. This part of town is called Zarechnii (“behind the river”), so named because it is separated from the rest of the city by the Ishim River and a stretch of countryside. The road that connects this small area to the city center is lined with small fields and gardens. The area around the school has the feel of a village, with single-story houses and dirt roads.

The school is a two-story white brick structure. Rows of windows with white curtains stretch across each side of the main entrance. Just inside the wide courtyard, a red brick tower stands to the right of the entrance, like an oversized chimney. This tower holds the elevator, added in the year 2000 to accommodate the new students in wheelchairs or on crutches who could not negotiate the stairs.

This elevator was only one of the modifications needed to prepare the school for children who had difficulty walking or who were in wheelchairs. A ramp now extends from the left side of the building so that children do not have to climb the stairs at the main entrance. Inside the school the doors have been widened so that wheelchairs can fit through them easily, and the

raised thresholds typical of Soviet-era buildings have been removed. Funds for these adaptations and repairs came from the regional budget.

The school is small, with only about 160 students and about 15 students in each class, Grades 1 through 11. Classrooms are small and could not hold many more students. Even with these small numbers, teachers work in two shifts, with half the students coming in the morning and half coming in the afternoon.

According to the director, the school is expensive to run, costing about twice per student what other schools cost. Part of this is due to the electric heating system, which is much more expensive than the centrally supplied hot-water heating systems that the other schools use. The low student-to-teacher ratio also contributes to the high cost of running the school. Other schools may have as many as 30 students in a single class. The teachers benefit from the small class sizes, but they do not get the supplementary salary that teachers in special schools receive.

The Center

The Center is also located in Zarechnii, not far from the school. This too is a two-story brick building with what look like slides descending from the second story along the side of the building. These are actually escape chutes. Students with limited mobility needed a way to evacuate the two-story building in an emergency; these chutes were the solution. The entrance of the Center has a ramp, but children in wheelchairs often get dropped off in the van at a dock in the back of the house.

The lower floor is dedicated to common areas, a kitchen, a living area, and a dining area. The director's office is also here. Two large fish tanks and a television stand near the entrance, and in the words of the Center's director, "Only the bathrooms don't have televisions." Many plants fill corners and windows throughout the building.

Mr. Shakshakbaev wanted to make the Center welcoming, and knew he had to overcome the anxiety caused by past experiences. Soviet education did not have a good track record with experimental projects. Institutions of all sorts in the Soviet Union could be very grim. He wanted ceramic dishes and colorful decorations to avoid an institutional feel that typified other institutions (Baimukhametov 2008).

The second floor includes the dormitories, with two children assigned to each room. At the end of the hall is a room for physical therapy with a range of different training apparatus.

According to Liudmila Yakovlevna Bondar, the director of the Center, the students' days are full:

At the [Center] the day is filled to the limit. True, for the younger students there is nap time, but for the rest of the time there is physical therapy, massage, art and music therapy, time with a psychologist and speech therapist, preparing homework. If necessary, the tutor always helps. It is never boring or simply relaxation; that way they get over bad moods quickly.

The director, two physical therapists, a speech therapist, a psychologist, and six tutors in different disciplines work with the students in the Center and also support them in the school.

Extracurricular Support

In addition to the school and the Center, a nearby club supports social inclusion by providing extracurricular activities. When the students are not in school, they have the option of participating in a range of activities at the club, which is sponsored by the Ministry of Education. Students have the choice of dance, music, theater, gymnastics, or art activities under the supervision of adult instructors. According to the club's director, nearly all of the students from School 13 participate in some activity there. During the site visit, we observed a short show at the club. Students with limited mobility participated, and classmates helped them walk up or down the stairs and move on stage.

The Origins of Inclusion and the Center

In 1995 Mr. Shakshakbaev awoke from surgery without his lower legs. He had once been an athlete but was now confined to a wheelchair. He suffered from systemic scleroderma and would also lose an arm before succumbing to the disease in 2005. Although he had graduated from a pedagogical institute, he had never worked in a school. But he began thinking of children who were in situations similar to his, and he wanted to help them.

"Where the idea came, I do not know," he wrote in a short published autobiographical sketch¹ (Baimukhametov 2008). But the idea of helping

¹ This biographical sketch is based on an autobiography published in 2008. The autobiography is included in Baimukhametov (2008).

provide children with limited mobility with a normal life and educational opportunity occupied the rest of his life. In School 13 Mr. Shakshakbaev is credited with developing the idea of inclusive education, not just locally but for all of Kazakhstan.

Mr. Shakshakbaev's autobiography recounts that some time after the surgery, he serendipitously met the former rector of the pedagogical institute where he had studied. After Mr. Shakshakbaev shared his thoughts about a rehabilitation center and encouraged students with limited mobility to attend regular schools, the rector suggested he write up a plan to realize this dream. Mr. Shakshakbaev thought of children with limited mobility and how he would have liked to be treated had he been in their place.

I imagined myself as a child invalid, looked at the world with their eyes. How they would want to live and where, how they study. What would gladden me? To what would I aspire?

At the time, opportunities for children with disabilities were extremely limited. Most students with limited mobility were confined to home tuition consisting of four to nine hours of study a week with a teacher. Because of the limited instruction, home study tended to produce poor educational outcomes, and it precluded further study at university or college. The limited time with a teacher did not prepare students to take the entrance exams. As Mr. Shakshakbaev writes, their lives become lives of dependency, learning no profession and no social skills that would allow them to work and live in the community.

Two "laws," conceived by Mr. Shakshakbaev, guided his plan: the "law of compensation" and the "law of adaptation."

The law of compensation obligates children with disabilities and their teachers to find what these children can do and to help them do it. For example, perhaps these children would not become great soccer players, but they could learn many skills and trades. Everyone has limitations, but those limitations should not define the individual. Mr. Shakshakbaev points out that not all students who study poetry become great poets, yet poetry is included in the general curriculum. Teachers and parents must look to what is possible rather than what is limited. This contrasts with the traditional approach to special education in the Soviet Union, which focused on deficits and remedying the disability instead of compensating for it. The specialists who worked with students with disabilities were, and still are, called defectologists. Defectology has a long history and has been

very influential in the Soviet Union and other countries of Eastern and Southeastern Europe (Daniels 2005). The founder of Soviet psychology, Lev Vygotsky, is considered to be the “father” of defectology, which emerged from debates during the 1920s and 1930s about the nature of handicaps (Florian and Becirevic 2011). Over time, defectology changed from an approach that understood disability as a bio-psycho-social phenomenon to a series of practices that emphasized deficits. Although some defectologists are at the heart of the inclusion movement in the former Soviet Union (Florian and Becirevic 2011), most Western commentators are critical of defectology and see it as a barrier to the development of inclusion because it focuses on limitations and recommends treatment in segregated educational institutions (Bartlett, Power, and Blatch 2004).

“If you’re deprived of something from nature or by the will of an evil fate, do not despair and make the most of what you are given,” wrote Mr. Shakshakbaev. He did his best to exemplify his law. Without legs and with one arm, he competed in the shotput from a wheelchair and placed first in the region and fourth in the country (Baimukhametov 2008).

The second law conceived by Mr. Shakshakbaev, the law of adaptation, is about independence. To the greatest degree possible, children with limited mobility must learn to be independent. This means learning a profession to earn a livelihood, but also learning to take care of themselves, learning to live independently. For this children must adapt. He realized the world could be harsh and did not pretend otherwise:

The world will not change. The world is cruel. It will not adjust for you. And if you do not want to stay away from life, if you want to participate fully in life—grit your teeth and adapt to this world. (Baimukhametov 2008)

He saw these laws as interrelated. One must use the law of compensation to adapt to the world and become independent.

After writing a plan, the former rector of the pedagogical institute introduced Mr. Shakshakbaev to the head of the regional department of education. They discussed the plan, and Mr. Shakshakbaev explained that he wanted to set up a boarding house for the children to support their education. During the meeting he argued against the status quo of confining children to home and bringing teachers to them. Instead he wanted children to attend one of the existing schools in the city. It was in this discussion that Mr. Shakshakbaev first learned the term “inclusive education,” from America. After considerable lobbying, he was able to access funds from the regional government to build the Center (Baimukhametov 2008).

The idea that the state should support special-education students was not new. The Soviets did this, but they did so in segregated schools and institutions where children would receive help from defectologists and other specialists. The idea that special-needs students should participate in regular schools and be socialized outside of special institutions was a clear break with the past. The regional department of education officially established the Center; it has since been transferred to the Department of Social Protection. The current official name is “Residential Home for Children with Limited Mobility.”

The final major part of the plan was finding a school willing to work with these children. According to the faculty at School 13, Mr. Shakshakbaev approached a number of schools, all of which refused the offer. In his autobiographical sketch, Mr. Shakshakbaev mentions only School 13. So began the collaboration between the Center and the school.

Inclusion in School 13

Despite the faculty’s willingness and preparation, the first years of inclusion, beginning in the year 2000, were the most difficult. The faculty at School 13 started early, during the summer, to prepare to receive their new students, who were to arrive at the start of the school year. According to the director,

We began preparing for the meeting with these students in June. We talked with parents, with teachers, with the faculty. Not all accepted the idea. Some had the opinion that these students would harm the teaching and learning. But there was also a great desire to help children, and the teachers supported me.

Despite the general sense of support, four teachers left the school. They did not want the added challenge and could not imagine themselves working with children with special needs, a teacher noted.

The faculty met with parents and each other to study and learn about ways of teaching the children. They did not receive help from the regional educational authorities at the time. Since then there have been opportunities for the faculty to take courses on special education at universities and attend national workshops.

The teachers began searching for information during the first year and continue to do so today. They read everything they could about psychology, pedagogy, special education, and inclusion. Most of what they found came

from abroad, because Kazakhstan did not have experience with these matters. Training continues. During the visit in 2011, an assistant director attended a special-education course in Almaty conducted by an American specialist. Recalling the early days of inclusion, the director noted,

We did not know how to approach these children, how to work with them, what needs these children have. This was the first time we saw these children. We started this work in June and July before these children came to us. We really started to read psychology, to read diagnoses of the children, to learn what cerebral palsy is. We studied and later in September we could recommend receiving these children, the entire faculty read. We all studied the literature, without exception.

During the interviews conducted for this research, it emerged that there were initial concerns about the proposed changes at the school, and questions were raised at the time. One question dealt with the changes that inclusion entails: “Why does my child have to look at those kinds of children?” Children with limited mobility had not attended regular schools in Kazakhstan previously. This question indicates that some parents saw the mere presence of children with disabilities as threatening. The parents and grandparents interviewed had never seen special-needs students when they were students in school.

The second concern involved the learning opportunities: “If these students [with special-needs] are in the class, how will my child get the attention she deserves?” Those families who were not convinced that inclusion was possible without harming their own children’s opportunities to learn exercised their right to choose a school for their children and left.

The director and the teachers worked closely with the families that stayed. “We invited them to lessons; we had parent meetings, home room lessons—this was very demanding work,” recalls the director. Her rationale for including children was of fairness. Referring to the special-needs children, she argues, “The children are not guilty; they live in our society. They do not need to be isolated.” This sentiment was repeated on several occasions.

“This tolerant relationship did not develop in one day, but over years,” noted an assistant director. “Now this work continues; this month is the month of support for invalids.” Activities during the month (October 2011) promoted inclusion as well as highlighting the success of people with disabilities.

The school now has a reputation as an inclusive school and is beginning to expand its services to support children with other types of special-education needs. For example, this has attracted two current students who

otherwise would attend a special school for hearing-impaired students, although it still probably deters some parents from bringing their children to the school. It probably has deterred some teachers as well. However, because of its good reputation, the school has not lost teachers or students as a result of its inclusive policy since that first year.

The regional Psychological-Medical-Pedagogical Commission (PMPC) selects children to live at the Center. The school faculty is not involved in this process and could not shed light on it. In general, parents and teachers can request that the PMPC assess a child. As implied, the commission covers psychological, medical, and pedagogical concerns. The PMPC then provides a diagnosis as well as recommendations for the education, intervention, and support such as speech or language therapy, physical therapy, or psychological treatment or special education. This commission controls the admissions to special schools, just as it controls admission to the Center.

Importantly, although children with other types of special-education needs attend School 13, the PMPC mainly selects children for the Center with physical impairment only. It is estimated that there are hundreds of such children in the region, but there is space for only 20 at the Center. The regional-level PMPC selects students who are physically disabled but have “normal” intelligence. Those with cognitive impairments are not admitted. Students are selected for the Center by the PMPC, based on its assessment of their ability to learn. As students graduate or leave the Center, new students are admitted.

Most of the students living at the Center have symptoms related to cerebral palsy, which affects muscle development and motor skills but can also affect vision, hearing, and speech, and can involve other health issues. Despite the emphasis on limited mobility in working with children with disabilities, emotional issues are often involved as well, especially for the older students who are attending school for the first time.

Mr. Shakshakbaev included a number of examples of students’ experiences in his autobiography, which not only highlight the challenges of the early years of the Center but also illustrate Soviet-era attitudes to disability.

Sergei and his mother were collecting coal near a railroad track. The poor often look for pieces of coal that have fallen from the trains and use them to heat their homes. Sergei fell under a train and lost both of his legs. He ended up begging at the city market and had connections with the local mafia. When he moved to the Center, even the mafia looked for him, and the police were involved. Sergei has big plans. In his own words: “I will not study at the university. I must help my mother now. I will finish college to learn a trade and later maybe study [at university].”

For Igor's first essay at school, he wrote, "If I were a magician, I would take a machine gun and shoot everyone—parents, teachers, students. Because I am an invalid and I'm useless to everyone." Igor's story highlights the difficulty of working with children with limited mobility. Having lived a life with so few opportunities and chronic dependency on others, Igor had emotional and behavioral problems as well. He was known to throw things at other students and at teachers. For this reason there is a psychologist at the Center and at the school. Igor now studies at a university. (Baimukhametov 2008)

During that first year, the PMPC chose children with the most challenging and most severe limitations. In addition, all 20 of them arrived together on that first day of school in the year 2000. These children had not been to school, had not received extensive instruction other than the few hours a week of home tuition, and had not received regular physical therapy. Nor did the regular students in School 13 know how to interact or help their new classmates. This required substantial adjustment for everybody.

As the students received regular physical therapy, and had the obligation to travel to and from and around the school, they developed physically, and many students showed remarkable improvement.

The difficulties were interspersed with comedy as well. As one of the early school graduates remembered, "My classmates wanted to help, they just did not know how. They would try to help and hold us, but then we all fell down." Curiosity got the better of some of the regular students who borrowed wheelchairs and rode them up and down the hallways. Mr. Shakshakbaev thought this was a good idea; it would give them an understanding of what it was like to view the world from the perspective of sitting in a wheelchair (Popova 2010).

Teachers and directors repeatedly said that they made many mistakes during the first years, but when questioned they only mentioned one: feeling too much pity for the new students. As a teacher noted, early on

we felt very sorry for these students... we were very concerned for them.... We increased grades for them. If a child does not raise his hand [to respond to a question], we give him a three. For these [regular] children we did not do this. We gave them a five [the highest grade]. It was difficult psychologically, morally, to look at these children.

One teacher went so far as to say that they tried to do everything for these students so that they would not have to do anything. According to the director, Mr. Shakshakbaev warned the teachers about this, and eventually they learned of the two laws and realized that they were not helping the students by making it too easy for them.

The director of the school said that it took about three years for the regular students to adapt to the presence of students with limited mobility. That adaptation is very obvious. The school day is set up in a series of 45-minute lessons with 10 minutes between them. In many schools, students can be very active and even aggressive during these breaks, running and pushing through the halls. This presents an obvious hazard for students on crutches or in wheelchairs. In contrast, at School 13, the students walked through the halls very calmly. During our visits, we saw a couple of students running, but they were the exception.

The first three years of socializing were difficult. Teachers worked with students in homeroom, individually, and worked with parents to teach them the new norms. This is an ongoing effort; even now at School 13, there are a couple of students who resist and need constant monitoring and reminders. It took effort every day. "It was during the fourth year that we noticed a big difference. Students had a more careful relationship with each other," remembers the school director.

In most of the classes we observed, there was a student or two on crutches or in a wheelchair. In every case at least one classmate, and sometimes two or three, assisted the students with limited mobility. One student might hold a bag while a second prepared the crutches, or one would fetch the wheelchair while two others helped the student stand from the desk and turn around. They did this without prompting or direction from the teacher. They managed without mishap.

It was ironic then to attend one class entitled "self-knowledge" that emphasized social skills and personal reflection, with the day's theme: "We are one team." The quiet atmosphere in the school and the obvious collaboration among the students indicated that they already worked as a team and needed no instruction on this topic. Although the teacher acknowledged this, he did note that the topic was part of the curriculum and he needed to cover it.

This emphasis on socializing played to the strength of the director.

Director

Two aspects of Ms. Maslova's experience prepared her well for working in a school beginning an inclusion program. One involved her work as a kindergarten director; the other involved her own daughter.

Before becoming director of School 13, Ms. Maslova worked for 20 years in a kindergarten. That position and its emphasis on *vospitanie* like-

ly prepared her well for the tasks of leading an inclusive school. *Vospitanie*, often translated as “upbringing,” focuses on instilling good manners and socialization. The teachers at the kindergarten level are called *vosпитatel*, emphasizing their role in the socialization of children. This contrasts with the title for teachers of Grades 1–12 who are called *uchitel*, a word with a common root with the Russian words for “to learn” and “to teach.” Much of the work during the first three years of the experiment involved developing new norms for student behavior.

Another, more personal, experience might have also encouraged Ms. Maslova to accept the proposition from Mr. Shakshakbaev. Soon after the birth of her first daughter, she noticed that her daughter’s legs were not developing in the same way. After several attempts she finally found a doctor who showed an interest and diagnosed a dislocated hip. For a year her daughter was in braces and eventually recovered and went on to study medicine. If it had not been for a few people willing to help, she would not have been able to attend school because of the expectations governing admission to school at the time.

Teaching and Learning

Although there is a strong emphasis on socialization, the school is also academically successful. Teachers at School 13 follow the national curriculum in all subjects and use the corresponding textbooks. With one exception, the teachers do not use the special curriculum that is used at special schools. In general, the teaching observed during the second site visit was didactic, and students were relatively passive. However, teachers often mentioned that the students were quiet because of the guests.

Many characteristics of the classroom environment are reminiscent of Soviet-era schools. Children sit in desks for two. Proper posture is sitting with arms folded elbow to fingertip, and students lift one hand so the palm is facing the side of the head to indicate a question or to respond to a teacher’s question. Teachers often remind students of this practice. Children dress formally, with girls often wearing a white blouse and black skirt and boys in black pants and white shirt. Some of the boys wear blazers or sport coats. Students stand when a teacher or an adult enters the room and when called upon to answer a question. Even students with limited mobility make the effort to stand when possible. Modern technology is also present. Almost every room has a smart board, which teachers often use for projecting PowerPoint presentations along with a computer.

In most classes there was some form of adaptation to accommodate students with special needs. The following scenarios based on classroom observations demonstrate typical adaptations seen during the site visits.

In a seventh-grade class taught by the school psychologist, the lesson was “We are one team.” The goal of the lesson was to emphasize that we live in society and must collaborate in one way or another. Most of the time was spent with the teacher using the smart board to show pictures and discussing what it means to live in a community. Typical and well-known examples were given: One stick is easy to break, while many sticks bound together are stronger. Another was the story about people given very long spoons. Those who learned to feed each other lived well. Those who did not learn to work together suffered for it.

In a discussion after the lesson, the school psychologist explained how he had to rethink his lesson and gave an example. The final activity in the curriculum for this lesson was a trust-building exercise that required students to stand in a circle with one classmate standing in the middle. The student in the middle closed his or her eyes and leaned towards the circle of colleagues. This would not work with the student who could not stand. The teacher therefore had the students all sit on chairs. This limited the sense of trust required to overcome the fear of falling to participate but allowed all students to participate.

The use of cards is a very common method of differentiation and adaptation. This is a method dating back to the Soviet era, to accommodate a range of students. Teachers prepare cards that give alternative tasks for students who cannot complete the regular tasks. For example, in a health class one student who does not write well is given the names of body parts to be sorted, while the other students wrote those same words. If teachers do not use cards, they prepare materials for the students with special needs. In one case, the teacher prepared a copy of the material that is written on the board for a boy who has limited vision.

Teachers have made other accommodations as necessary. One teacher practically shouts at a girl who is hard of hearing. Sometimes accommodation involves collaboration. In a math class a colleague pointed to figures on the board while a student with special needs responded to the teacher’s questions and described the characteristics of the geometrical shapes.

In the ninth-grade class, the school director admitted that the students were all well-developed intellectually, so there was no need for modifications, nor were any seen in the lessons that were visited. This also may be the result of intensive intervention in the lower grades, as claimed by the faculty.

There was a physical-education demonstration lesson during our visit focusing on the inclusion of students with limited mobility. During the lesson, two teams, both with students with limited mobility, competed in individual and group activities. During a shuttle run, a student in a wheelchair simply wheeled back and forth with the help of a fellow student. Another activity required students to slide along a bench on their stomachs; a couple of students could not do this, and they simply walked or wheeled around the bench. To assemble a jigsaw, both groups formed circles around the puzzle pieces arranged on the floor. In all activities, all students participated as much as they could.

Teachers do not work alone. Tutors from the Center accompany some of the students every day. During our second visit, they often sat in the back of the classroom and observed. We did not see them active in the lessons at all. At times the teacher helped the special-needs student while the tutor looked on. This may have been due to the presence of the researchers. According to the teachers, the tutors did not want to disturb the lesson while a guest was present. Popova (2010) reports that the tutors do take on more active roles, including working with students individually if the lesson becomes too difficult or other problems arise. For example, they can work with the student individually or take the student from the class if the group work becomes too difficult or the pace too fast.

Despite the challenges and accommodations, various assessments indicate the faculty and students have been very successful in including children from the Center and ensuring their learning and participation.

Assessment

Assessment at School 13 is personalized. All students have a portfolio, as required in national education policy (although teachers at School 13 were not sure that all other schools follow this policy). This portfolio contains examples of student work, writing samples, and exercises from different subject areas. This may be simple drawings, essays, or artifacts from larger projects. After 10th grade, the portfolio is used to inform decisions about career recommendations and further study. The emphasis and usefulness of the portfolio is to “show growth,” not to evaluate, noted the director. The portfolio is also useful during the first two years at school; during those years students are not graded. “We don’t want to give grades so early. Students might think that this is the best they can do and not try to improve,” explained an assistant director.

Despite the generally positive atmosphere in the school, at the end of the lessons teachers were not reluctant to give grades and praise or criticize students in front of the class. This might involve criticism for being slow, or making mistakes. This was a common Soviet practice. In a more progressive twist, two teachers asked students to evaluate their own work during the lesson.

Because students with limited mobility were now enrolled in School 13, they also had the opportunity to take the final examinations (known as the ENT) that determine college entrance. This too presented challenges. Some of the children could not fill in bubbles on the answer sheet accurately because they lacked fine motor skills. They eventually got permission for a non-subject teacher to fill in the bubbles that the student selected. During the first year that students with disabilities participated in the ENT, there were problems when they came to the designated building, which did not have ramps or other adaptations to permit the students to enter on their own. The students with disabilities had to be carried by other students into the examination center.

School 13 is a successful school by at least two measures. According to the results on the ENT, students continue to improve their achievement. ENT scores have increased over the past few years, and the average scores for different subjects at School 13 are at or above the averages for the city (Popova 2010).

The school has many successes with inclusion, and not only with students with physical disabilities. Vika, a former student, not only had damaged legs and arms but also could not speak. When she came to the Center, she should have been in the 10th grade. But her mother had died, so she lived with an elderly grandparent and had received very little education. Because of this, she was placed in the fifth grade. Teachers at School 13 worked with her and tutored her after school. Eventually she gained entrance to a local college.

School 13 is rightly proud of the students with special needs who have studied, graduated, and attended post-secondary schools. Their pictures adorn the entrance to the school. Some have attended colleges where they are learning a trade and profession. Others attend universities. Although Kazakhstani law guarantees the right of children to study in schools, they only have the right to compete for admission to post-secondary institutions. The students who continue their studies have earned that privilege. Many of the graduates have gone into information and communications technology (ICT). This is not by accident. For students who cannot easily hold a pencil or pen, working at a computer allows them to type.

Without the Center and without the school, the possibility for further study would not have existed for these students.

How do teachers attain this academic success given the challenges? The director says that they “analyze exam results to learn where students need help.” Mostly, this extra help comes in the form of extra lessons after school. Parents noted that “at this school teachers do not take extra money for tutoring, unlike teachers at other schools.” The director agreed that the teachers here do not take money for tutoring but would not comment about teachers at other schools.

According to the director, individual attention is the secret to the teachers’ success. When teachers see that a student needs extra help, they often provide it through additional tutoring. “When there are many [students] there is not much progress; when there is one, there is great progress,” the director points out. Repeated questions about other teaching methods elicited neither clarification nor elaboration, but undeniably, the additional support provided by the Center contributes to the success of the students. Good relationships between the students and adults are also apparent.

Students

Periodically the teachers talk at length about how to interact with students with special needs. For instance, they meet once a quarter in a “discussion club” to discuss topics relevant to the students’ lives. During our visit in 2011, a group of graduates took part.

When they arrived in the classroom for the meeting, they greeted each other like good friends or family, perhaps because they lived at the Center together and were among the first special-needs students to study at School 13. All of them had studied at post-secondary institutions, and several were working. This alone is a tremendous success for students who otherwise would be confined to their homes.

The first question these graduates and other students asked me was, “Are there such schools where you come from?” I then asked what kind of school this was. The students responded that it was a school with both special-needs and regular students studying together. When I explained that this was legally required in the United States, all of the students expressed their approval, smiling or giving a thumbs-up sign.

The former students repeated that they were thankful for the opportunity to attend the school. As several mentioned, “The school helped us to

become more sociable and have friends.” Given the alternative, and perhaps some nostalgia for the time this group had together, this is very significant.

One student during the first site visit said that at School 13, “we take responsibility for special-needs students.” During the second visit we posed this question to other students. Several groups of students responded in the same way.

Others are afraid of not finding a common language with this type of children, but we are not afraid; we can assume this responsibility and we are proud of that. For example, with Andrei, the 11th-grade student, everyone communicates and is a friend of his; so are we, and we don't feel the distance between him and us. (Eighth grader)

Although this sentiment is positive and reflects the benefits of having special-needs students in the school, it does show that students are aware that in other schools such opportunities are not available.

Parents

During the visit in the fall of 2011, we were able to speak with five parents or grandparents of both special-needs and regular students.

One parent, Oskar, had a daughter who was born deaf. At the age of four, the girl had an operation performed in Almaty by a French surgeon that gave her some hearing. At the recommendation of a teacher in Petropavlovsk, the parents visited School 13. The teacher felt that this school would be good because of the “small classes and accommodation” and “warm atmosphere.” After a visit, the parents agreed. Every day the father travels by public transportation from the city to the school twice. He is pleased with the work of his daughter’s teachers: “There has been progress—not great progress, but progress.” But he notes that there are limited options in Petropavlovsk. There are no other good options in the city: “If I had the resources, I would send her to Astana [the capital city].”

Oskar receives about U.S. \$200 per month to cover some of the costs of having a disabled child. When asked, he noted that this was not a lot of money but was still a significant contribution to the family finances. Parents with children at the Center also receive similar sums, even though the children live at the Center.

The other four grandparents or parents interviewed were pleased with school. Interestingly, they had never heard the terms “inclusion” or “in-

clusive education.” Even though they had not seen such students when they themselves were in school, they were glad that their children and other students had the opportunities that they did. Unfortunately, we were not able to talk with parents who had chosen not to send their children to School 13.

To convey the sense of relief and appreciation afforded by the Center and School 13, included below is a letter that Mr. Shakshakbaev quoted in his biographical sketch. This letter is from a parent whose son’s legs did not develop, for reasons unknown.

So I resigned myself to the fact that my son was an invalid. He was registered as a person with a disability and began to receive benefits. It was clear that I had to say goodbye to my work. And the work I had at that time was prestigious and highly paid; I am a certified public accountant.

Two years ago we were offered a place in the new boarding school in Petropavlovsk. And then, as luck would have it, I got sick and fell ill in hospital. His place was taken by another. I am not upset, I’m already reconciled with misfortune in life. But sometimes fate smiles on me. Six months later I was summoned to the district’s education department and was told that we were on the boarding school’s list; they remembered us, and we waited for the next academic year.

And now my Amantai has spent a year at the boarding school. None of our relatives can believe that this is Amantai. He is a completely different person. He was always grim, taciturn, and irritable, talking with no one.... And now he is all lit up with cheerfulness. When the weekend comes or he is at home for the first few days of a vacation, he does nothing but talk about his new life. And then, when all the talk is beginning to get boring, I see that he is reaching back into the city, to the boarding school, to friends at the boarding school, to friends at the school where he studies with normal children. And if you could only know how happy I feel. Yes, I’m to blame, this is not my forgiveness. But now my son lives with light, with a future, and because of this it is a bit easier for me. We mothers have one motto: “As long as I live—I hope.” Here and now, I hope that my son’s life will be fine.

Plans for the Future

Ms. Maslova is open to having cognitively impaired students in the school. When asked if such students should study at the school, her response parallels the response given when asked about students with physical disabilities: “Why not? Are they guilty, such children? It is very important [for them] to socialize with [other] children.” There was one girl who did come to School 13 from a special school boarding house. She was learning- and physically disabled. To work with this girl, the teachers used the program from the special school. The girl finished eighth grade

and returned home. Starting an inclusive program has led to growing inclusion at School 13 as the staff has learned about inclusion by making it happen.

Conclusion

Michael Fullan (2001, 45) has written, "Educational change is technically simple and socially complex." In the case of School 13, the social aspects of implementing inclusion took time but seem to have been resolved. Although Mr. Shakshakbaev and Ms. Maslova were perhaps motivated by their personal experiences, the idea of inclusion had a strong enough appeal to the school community that it has become the new norm. Promoting inclusion has relied on three levels of appeal.

First is the right of the child to education. As we heard several times, the special-needs students have done nothing wrong and so should not be deprived of an education or the opportunity to socialize with other children.

Second, the school is richer for the presence of special-needs students. Faculty and students and parents all felt that the school was better because of the children. Regular and special-needs students have become friends and help each other.

Third, all students have potential. School 13 proudly displays portraits of its successful graduates. These students have gone on to study at colleges and universities in Kazakhstan and Russia, demonstrating that inclusion and high achievement are compatible.

These appeals could help encourage other schools to include students with special needs, but expanding inclusion into other schools will take a great deal of effort, not just a logical or moral argument. Furthermore, the faculty of School 13 did not only include students with special needs based on a theory. They were motivated by others and were convinced to try. They have obviously worked very hard to develop the culture and the skills to bring the students to the school and work with them effectively. This work did become easier over time as the school community accepted the new students and teachers learned how to teach them.

On the technical side, although the faculty of School 13 has made tremendous progress, there are limits to what we can learn from this case. This does not take away from the success of School 13. First, the Center obviously contributes a great deal to the success of inclusion and the students. With the psychologists, special-education teachers, and tutors sup-

porting the students, success become much easier. Not every school will have such a well-staffed center supporting the school. Second, School 13 does not have much experience working with students with cognitive impairments or other special needs. When such a student attended the school, the teachers used a different curriculum. Including students with cognitive impairments will present all of the challenges of including students with limited mobility plus many more pedagogical challenges. The range of teaching methods seen at School 13 will need to be expanded in order to work with a broader range of students.

A wider range of teaching methods will have a limited effect if teachers must strictly adhere to a standard curriculum. School 13 does follow the national curriculum, but when a student with cognitive impairment enrolled in the school, the faculty “borrowed” the curriculum used in special schools. Expanding this practice would limit the amount of participation for the students and challenge the inclusive nature of the school. Teachers will need to develop expertise in a wider range of methods in order to teach a broader range of special-needs students. This may require greater flexibility in the national curriculum or more creative ways of working. The school’s success with Vika and the progressive approaches to assessment provide some encouragement here.

The various professionals currently working in special schools and institutions could provide a resource and ameliorate some of these challenges, but many do not have experience with inclusion, and because of their separate training, most will not have worked in regular schools. There are unlikely to be simple solutions in redefining special schools and institutions as resource centers, although some defectologists have started to work in more inclusive ways in many other countries (Florian and Becir-*revic* 2011). At the national level, policies and policy goals that support inclusion are already in existence. School 13 did not have the benefit of public awareness campaigns to support inclusion. However, large-scale media campaigns may help with public awareness and facilitate the expansion of inclusion both in terms of the number of schools accepting children with special needs and the kinds of students accepted at regular schools. Some sort of incentive or enforcement may be necessary to encourage reluctant teachers and administrators to comply.

The establishment of the Center made it possible during the past decade for a number of children with disabilities to be included in a mainstream school, and this is a notable achievement. However, it also raises questions about sustainability. In addition to the Center’s cost, its existence presents a challenge to the development of inclusive programs na-

tionally. It is ironic that in order to be included in a regular school, many students with special needs who attend School 13 must live in the Center separated from their families. The alternative—having students live with their families and providing transportation to and from school—would also be expensive, but it would not entail separating children from their local, natural systems of support. If the country is to meet its goal of including children with special needs in 70 percent of schools by 2020 (MOE 2010), having students live with their families would be much more feasible and sustainable. Such an aspiration would require a major training initiative, not only to increase the number of specialists who are qualified to work with special-needs students, but also to build capacity in mainstream schools so that they can educate more children with special needs as close to home as possible.

School 13, with the support of the Center, has made tremendous steps forward by successfully including students with disabilities. They have done so not because of their extensive knowledge of special and inclusive education, but because they wanted to and were willing to work to achieve that goal. Ms. Popova used the following quote to exemplify the ambition of School 13's faculty: "Those who want to can do much more than those who can" (Popova 2010). Change will require leadership, but success can come with the effort of those teachers who are willing to lead the way, learn the lessons, and share them with others.

Were these successes achieved by "fools who rush in"? Not only are they good people, but their work through the Center and the school, together with their colleagues, parents, and students, exemplifies what can be achieved when motivated individuals decide that greater opportunities should be provided for children with special educational needs. Inclusive education is created one school at a time, and this case demonstrates but one example of the first steps to creating more inclusive educational experiences for children with special educational needs. Although the circumstances of School 13 are specific, the lessons emerging from this case study have wider applicability in Kazakhstan and across the region.

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“Raising Children without Complexes”: Successes and Shortcomings in Implementing Inclusive Education in Northern Kyrgyzstan

Cassandra Hartblay and Galina Ailchieva

Natasha and two of her classmates are giggling and grinning by the door to their classroom. Today is their day to give a presentation to the rest of the class, and they are giddy at the opportunity to be the center of attention. Their classmates, a blur of fifth-grade energy, are calling across the room to one another, comparing sneakers, arranging notebooks; a bell rings, and the ruckus subsides. Their cultural heritage teacher moves to the center of her space at the head of the room. She wears a straight calf-length skirt and a turtleneck sweater, her long black hair arranged in the Victorian up-do of the Soviet intelligentsia. She is a longtime senior teacher; her eyes glimmer with intelligence and the patience of many years at the head of the classroom. She tells me later that although she is ethnically Kazakh, she grew up in southern Kyrgyzstan and so speaks fluent Kyrgyz as well as Russian and Uzbek. At BS3, she teaches the Kyrgyz language and *etnokultura*, or cultural heritage lessons.

“Today,” she tells the class as it comes to order, “your classmates have prepared a puppet show for you. Can someone tell me what we are learning about today?” A few students raise their hands. “*Konniye igri* [equestrian games],” replies one student.¹ Natasha, who has been attending the

¹ The Kyrgyz people, as pastoral nomads, identify as horsemen; the great cultural hero Manas (the Kyrgyz Odysseus) is memorialized on horseback in the central square in Bishkek. This cultural heritage was carefully established through the tradition of Soviet ethnography and canonized as an element of cultural knowledge. Since Kyrgyzstan achieved independence, the subject of cultural heritage has been added to school curricula (and a project is currently underway to standardize national curricula), with the intention of passing on the national identity to new generations.

school since the first grade, has cerebral palsy. At first walking was difficult for her, but she has since learned to walk freely, if a bit slowly; she writes and draws well, though with less control than her peers. With shaggy blond bangs and a quick smile, Natasha is popular among her classmates and well-loved at the school. Her presentation this morning is with two fellow students, one of whom has recently come to the school after his family moved to the area from the south, and who is still struggling to learn Russian.

Natasha and the other presenter, standing behind a screen at the front of the room, illustrate the tale with a puppet show using toy horses and dolls. Next, Natasha recites a poem she has memorized about horsemanship, her voice firm and eyes gazing into space at the back of the room. She slips up and forgets a line, looking to the teacher, who prompts her. Afterwards, she takes her seat.

The teacher holds up a picture of one of the traditional games played on horseback at festivals. She asks the children—who have seen the games played on holidays—to state the rules of the game. Natasha giggles along with the rest of the class when the object of one game is discussed—it is for a young man on horseback to chase a girl riding her own horse and try to give her a kiss on the cheek without dismounting. Another involves picking up a coin from the ground while riding past.

The final component of the lesson involves the vocabulary for all of the elements of dressing a horse to be ridden. The boy from the south, familiar with horses and therefore with all the terminology for tacking a horse, is given the task of naming and explaining each item—pictured on a poster—to his peers. He struggles with the Russian, pointing in turn at each item in order, and attempting to describe how to put it on the horse. The teacher prompts him when he can't find the right word.

Introduction

This case study recounts efforts to implement and sustain inclusive education in public schools in the medium-sized town of Belovodsk, Kyrgyzstan. The inclusion of children with special needs in public schools in Belovodsk initially represented a “top-down” approach to inclusive education, in that the initiative to implement inclusive education there is the result of partnerships between the Ministry of Education of Kyrgyzstan and the USAID-funded Participation, Education, and Knowledge Strengthening (PEAKS) Project, which was implemented from 2004 to June 2007.

Using a sociocultural approach and ethnographic research methods, this case study explores why a commitment to inclusive education has taken root in Belovodsk even though the initial donor funding for the project ceased nearly five years ago. We found that diverse stakeholders in Belovodsk came together in public-NGO partnerships to build more inclusive school environments and access to education for children with mobility and sensory impairments in a provincial town. The outcomes and impacts of this continuing initiative, documented here, represent a significant achievement in the inclusion of children with special needs in public education, and the fostering of a more inclusive environment in the broader community. However, challenges remain in terms of spurring parent involvement, fostering broader awareness of principles of inclusion, extending inclusion to children with severe and multiple disabilities, and in preschool and early intervention programs. Furthermore, the Belovodsk example will be more difficult to implement in more rural and remote regions.

Belovodsk in Context, Kyrgyzstan in Transition

Belovodsk is located 40 kilometers from the capital city of Bishkek.² Belovodsk is bigger than a village but smaller than a city. Located on a main highway heading south from Bishkek toward Osh (two lanes, with a parade of shops, mosques, churches, open-air markets, and auto body shops lining the dusty pull-offs), it is for many a place merely to pass through. However, as the administrative headquarters of the northwestern-most region, Chui Oblast [see Table 1 on page 118], Belovodsk is home to a government administrative building. Along with regional governance, a bazaar-style marketplace and a regional hospital (located about half a mile apart) are the major attractions to outsiders. During the Soviet era, in addition to the government jobs in schools, administrative offices, and the hospital that still exist, there were several factories that propelled the local economy. Now, however, only two major factories are still functioning—a brick factory (which produces bricks for construction) and a dairy works (which makes butter and cheese). Even the bread factories closed down during the difficult years after the dissolution of the USSR.

² Bishkek has an urban sensibility and several universities; as the seat of the government and national arts, it is the high-culture capital of Kyrgyzstan (while the city of Osh in the south is regarded as the unofficial capital of folk tradition, especially the cowboy/pastoralist lifestyle that the Kyrgyz identify as the core of their cultural heritage).

Moreover, the demographics of the town are changing. The economic situation throughout Kyrgyzstan remains dire. While some with advanced degrees are able to find work with government agencies and international development organizations in Bishkek, those outside the capital, including in Belovodsk, find that there is little economic opportunity in their communities. For those who hope to make some money to better the situation of their families, migrant work is often the best solution. Many ethnic Russians who grew up in Belovodsk have left for Moscow or other regions of Russia, where economic opportunities are greater. Some send remittances home to family in Belovodsk. Other families depart *en masse*, leaving their homes in the care of neighbors or friends. Meanwhile, southern Kyrgyz and ethnic Uzbek Kyrgyzstani citizens are moving into the Belovodsk region; the town's proximity to the capital, and to the border with Kazakhstan, afford greater economic opportunities than are available in the country's south. Living in Belovodsk, where the language of commerce is Russian, provides a stepping-stone for those from the south who hope to become migrant laborers to Russia.³

This internal migration is, considering the ethnic tensions that erupted in the south in 2010, not without problems. Northerners remain wary of southerners, whose different ways and linguistic and religious preferences they regard as uncivilized compared to the more urban cultural life cultivated by the northern educated classes.

Belovodsk occupies an odd middle ground in the hierarchy of provincialism. Oriented toward Moscow, Kyrgyzstan itself is perceived by its residents as small, impotent, and without economic or political clout. Compared to Moscow, the capital of Bishkek is seen as a small and provincial city, if stolidly intellectual and committed to a heritage of Soviet modernity. Compared to Bishkek, Belovodsk is a small and boring town, with "nothing to do" and few economic opportunities. However, compared to southern Kyrgyzstan, Belovodsk is considered stable and peaceful, modern, and close to the city. It is seen as a place of possibility in that

³ Many Uzbek- and Kyrgyz-speaking families send their children to Russian-language elementary school. With both Russian- and Kyrgyz-language public schools available, children can be educated in the language of their parents' choice (Korth and Schultze 2003). Once placed in a Russian-language school, these youngsters struggle to learn in an unfamiliar language but become proficient enough in Russian to become a salesperson or laborer in Russia once they reach their teenage years. In this way, teachers in public schools in Belovodsk are already working out special-education lesson plans to accommodate the needs of those children who do not speak, understand, or write well in Russian.

it seems to be at the fringes of modern urban culture, rather than in the more pastoral south, which is perceived as beyond the reach of development.

These factors made Belovodsk an attractive place for public-private initiatives with headquarters in Bishkek to work out how to institute inclusive education for children with disabilities. Belovodsk is close enough to visit on a day trip from Bishkek and is a local regional administrative headquarters, which means that the Ministry of Education has a district office there.

Symbolically, too, Belovodsk is a relevant place to implement a new way forward for including citizens with disabilities. It is home to the country's only state institution for people with disabilities (conditions at the institution were not reviewed during the course of this study, but were resoundingly described as “depressing,” emphasizing the lack of hope for the future that settles over those who end up there). During the Soviet era, there were three such *internati*—the other two have since closed, as the state consolidated services in favor of this region, based on its proximity to the capital and its *internat's* superior reputation.

The level of stigma surrounding disability in the Belovodsk area cannot be overestimated. People are not accustomed to seeing others with any kind of visible disability out and about on the streets of the town. The mother of one young girl with cerebral palsy recalled the experience of taking her daughter with her to the corner store. “Even when she was just a toddler,” she told us, “people would stop me and say, ‘Why are you bringing a child like that around here? She should be kept somewhere away from the other children.’” Popular wisdom holds that children with even a mild physical difference—like a harelip or a missing limb—ought to be kept away from the general population, either institutionalized or restricted to the family home. Not only physical differences but also sensory and intellectual impairments are assumed to be due either to a family's weak genetic lineage or the result of some moral failing. At the professional end of this spectrum is the habit of Soviet doctors of broadly accusing mothers of drinking during pregnancy; at the superstitious end, the assumption that some bad behavior has brought a punishment upon the family. Anecdotes circulate of families hiding children with disabilities from friends, neighbors, and even extended family in order to protect the reputation of parents and “normal” siblings.⁴

⁴ On the subject of social stigma as a barrier to inclusive education, Djumagulova (2004: 128–129) writes:

These attitudes are not limited to village old wives' tales. A fellow researcher, who is studying for a doctoral degree in social work, recounted a telling anecdote. One of her good friends from her graduate program suddenly became very distant after giving birth. After two full years, the friend finally revealed that she had given birth to a daughter with cerebral palsy. Even knowing that her friend worked on disability issues and so was likely to be accepting and supportive, the new mother was so frightened of becoming socially outcast if her peers found out that she completely withdrew socially. Ableist attitudes like these have a profound impact on access to education and inclusion in all realms of life (Hehir 2005: 8; Linton 1998).

Top Down: The Legal Context

One of the challenges facing the realization of inclusive education in all regions of the former Soviet Union is the legacy of a state system that 1) systematically separated and institutionalized children with disabilities, and 2) developed "defectology," an approach based on the ideas of Vygotsky with an overlay of Marxist ideology, which treated disability as a product of biological, psychological, and social factors. Although on the surface this sounds like the "social model" of disability, in fact, it tended to view a child's disability as the product of either a biological or social failure by the mother (Iarskaia-Smirnova 1999; Daniels 2009: 29–45). Some former Soviet citizens observe wryly, when asked about disability, that in the past they thought only capitalist countries had people with disabilities, because such "problems" were said to be the result of class warfare. As is well-documented, citizens with disabilities were ignored during Soviet times, aside from the minor attention briefly given to war veterans following World War II (Krylova 2001; Dunham 1989; Phillips 2009 and 2011; Gallego 2006; Kikkas 2001; McCagg and Siegelbaum 1989). At the same time, special education for deaf and blind children at residential

"Fear, taboo, shame, lack of knowledge, misinformation and socio-economic values about human life, respect, and dignity all encourage negative attitudes towards disability. The impact of such attitudes is evident in the home, school, community and at the level of national policy making in terms of planning, budgeting and programming. At the household level, children with special needs and their families often develop low self-esteem, hiding away and shunning social interaction, which can lead directly to their exclusion from education... fearing for their safety, or for the respect and honor of the family, parents sometimes lock their children with special needs in the house when they have to go out, or hide them completely so that neighbors may not even know they exist."

schools in regional capitals was targeted toward vocational programs in sheltered workshops, and critical disability scholars from the West at one time found some Soviet policies more malleable than policies back home (Dunn and Dunn 1989; Sutton 1980). However, the core issue that remains in implementing inclusive education from the top down is the problem of how to implement civil law in a society with little history of recognizing civil rights or classes of people denied the exercise of their rights.⁵

In Kyrgyzstan, the 1992 Law concerning Education in the Kyrgyz Republic was drafted based on the principle that all citizens have the right to an education, although segregated education is clearly envisioned for children with disabilities. Article 27 establishes that for "children requiring long treatment, education and treatment can be organized in sanatoria. Lessons can also be provided in hospitals and homes." Article 29 establishes that for "children with intellectual and physical impairments, special schools, classes, and groups will be arranged to provide joint education and treatment. The medical commission will direct children to such centers with consent of the parents" (Djumagulova 2004: 81). Thus, inclusive provision in general education schools is not forbidden by law. Parents have the right to consent (or not) to the placement that the PMPC recommends.

Demographics

There are five public schools (serving first through 11th grade) in the Belovodsk area. Each is attended by a handful of children with special needs. Two of these five schools, Belovodsk School Number Three (BS3) and Pervomaiskaia School, were visited as part of this study. According to the town records, 68 children under the age of 18 are classified as having a disabling diagnosis sufficient to receive a social benefit monetary stipend (3,000 som/month⁶). Of those 68, 14 have cerebral palsy (DTsP), and two have HIV/AIDS. Children with diagnoses including hearing and vision impairment, mobility impairment, and mild learning disabilities were also attending school and receiving services based on the inclusive education initiative. Educators also reported a growing number of children with hyperactive habits and speech impediments, whose educational needs were

⁵ While, for example, the civil rights movement in the United States laid the groundwork for the Rehabilitation Act (1973); the Education for All Handicapped Children Act (EHA) (1975), which later became the Individuals with Disabilities Education Act (IDEA) (1990); and the Americans with Disabilities Act (ADA) (1990). See Valle 2009.

⁶ Approximately \$63 at current exchange rates.

being addressed using individual education plans or the tools of inclusive pedagogy. Children with temporary medical problems that kept them homebound, or long-term illnesses or disability requiring hospitalization, were assessed by educators and parents, and out-of-school instruction was provided as necessary. No children with Down's syndrome, severe cerebral palsy, severe intellectual disabilities, severe psychiatric diagnoses, or medically uncontrolled conditions (as defined by guidelines outlined by the manual of the Commission on Diagnosis) were receiving education in general-education schools as part of the initiative at the time of this study.

Table 1: Demographics at a Glance

Chui Oblast	14,982 children in the school district 48 are not receiving education of any kind (some are working in the fields with parents) 84 children with special needs are studying in schools or partnering with schools for home education 37 are at <i>internati</i> (residential specialized schools or institutions) [data from Belovodsk Municipal Social Welfare Office]
Belovodsk Township [<i>Belovodskoye Selo</i>]	6,868 households 1,417 households receive some kind of social support—many also rely on their own vegetable gardens for food security 16 percent live in poverty (2010 town records) Ethnic identities (officially documented according to Soviet ethnic group lists in the current Kyrgyz passport, and often reflected in language spoken at home) include Kyrgyz, Russian, German, Ukrainian, Dungan, Uzbek, Tajik, Kurdish 68 children under 18 have disability status [data from Belovodsk Municipal Social Welfare Office]
Belovodsk School Number Three	833 students 53 percent female 8 children have vision impairment 35 have some sort of developmental delay [data as reported by staff from school records]
Pervomaiskaia School	1010 students 58 percent female 46 children with diagnosed special needs, not necessarily at the “disability” level, including: • 5 children with mobility impairments • 22 children with vision impairments • 4 children with speech impairments • 2 chronically ill children • 9 children with intellectual disabilities [data as reported in public records]

Research Methods

The findings presented in this case study are the product of collaborative research. Galina Ailchieva, a trained defectologist and specialist in the Ministry of Education, began the evaluation of this case study site with support from the Open Society Education Support Program in 2010. Ms. Ailchieva conducted site visits at the two primary-secondary schools, focusing her research on the experience of one young girl with cerebral palsy at Belovodsk School Number Three. At this phase of research, Ms. Ailchieva observed class lessons; interviewed the school director and teachers; and in cooperation with a teacher at the school, devised a class assignment that was used to survey the attitudes of children toward their peers with special needs and assess their attitudes about inclusion.

In the fall of 2011, Cassandra Hartblay, a PhD candidate in cultural anthropology, specializing in disability issues in the former Soviet Union, joined the research team. Drawing on her knowledge of initiatives to implement inclusive education in the Russian Federation, Ms. Hartblay cooperated with Ms. Ailchieva to further document the successes and challenges in establishing inclusive education in Belovodsk.

In mid-October 2011 both researchers convened in Bishkek and then traveled to Belovodsk. Ms. Hartblay spent five days living in an apartment in Belovodsk in order to better understand local day-to-day life. Over the course of 10 days, the second phase of field research was conducted collaboratively.

Research during this period included classroom observations; interviews with school personnel, including directors, school psychologists, and classroom teachers; interviews with four parents of children with disabilities at BS3 and with one parent at Pervomaiskaia School; a voluntary written survey of parents from BS3 with eight respondents; informal conversations with students; a mapping exercise with one of the students with a disability; a visit to the home of a student who studies remotely; visits to non-school educational institutions; interviews with relevant regional scholars; interviews with local social workers and education officials; and collection and study of relevant administrative documents, such as diagnostic protocol and manuals for implementing inclusive education. Data included handwritten field notes, digitally recorded interviews, digital photos and video clips, survey responses, hand-drawn maps of the school, and the relevant documents.

Potential biases arising from the methodology of this study include 1) Ms. Ailchieva's insider status as a member of the team seeking to institute inclusive education practice, and 2) Ms. Hartblay's bias as a Westerner concerned with implementing greater inclusion. Thus each researcher was faced with the challenge of establishing rapport with local collaborators, to prevent a Potemkin-village effect in how local stakeholders reported the degree of inclusion, and the challenge of stepping outside their own goals in perceiving the needs and interests of the community. Additionally, only Russian-language schools were included in the study.

Methodological Orientation

In order to understand the role of inclusion and special education in Belovodsk, this case study considers disability, and responses to disability, as a sociocultural phenomenon. As such, disability cannot be understood only as a medical-psychological-developmental diagnosis but as created by a complex interplay of sociocultural factors (Skinner and Weisner 2007: 303; Ingstad and Whyte 1995).

Fundamental to this research is an understanding of disability that recognizes that the most important influence on a child's future is *not* his or her diagnosis, but the sociocultural *place* where (s)he will grow up. While diagnosis, services, and biomedical interventions are critical elements of a child's development, all of these interventions unfold in a sociocultural context, or place, that includes "not only the geographic locale and ecology, but the local community and its resources and ways of life, and its shared beliefs about development and disability" (Skinner and Weisner 2007: 302). That is, the name for a child's disability, whether it be cerebral palsy, Down's syndrome, or hearing impairment, has less to do with the child's life chances than does careful attention to the kinds of social factors, including stigma and opportunity—not just in the family, but in the broader community and school—that characterize the local environment in which (s)he will grow up.

This method favors qualitative illustrations rather than quantitative measures as empirical evidence, and, in particular, the strength of the ethnographic description to track complexity in context. As Skinner and Weisner suggest, the research that makes up this case study brought the researchers "into the living rooms, classrooms, service centers, after-school programs, Sunday schools... and other social settings where those with disabilities and their families [and educators] go about their daily lives" (2007: 303).

Utilizing a sociocultural ethnographic approach, this case study also serves as a review of the successes achieved to date and the challenges that remain in establishing inclusive education in Belovodsk. This formulation, in attending to the goals of diverse stakeholders, tracing implementation and impact, and collecting stakeholder perceptions of the initiative’s sustainability, aligns with a methodology that Maude and DeStefano have developed to explore the degree to which early childhood special education programs are meeting their stated goals (2011: 150–160). In formulating this research, we oriented our inquiry around three basic questions: *How has inclusive education in Belovodsk come into being? What challenges still remain? And what useful lessons for future programs can be extrapolated from this case?*⁷

Thus this paper will proceed by 1) delineating the goals of the Belovodsk inclusive education program (as stated in archive materials and articulated by stakeholders); 2) reviewing the implementation of the program, such as how and with whose cooperation the program has emerged as it currently exists; 3) assessing the effectiveness of key components of the program, particularly how the opportunities available to children with disabilities and their families have emerged thanks to the program; 4) sketching the impact of the program thus far by relating ethnographic examples of participation in the program; and 5) addressing the sustainability of the program, in terms of observing what steps can be taken to further establish inclusion as a part of public education in Belovodsk and listing remaining opportunities and barriers.

⁷ Each of these three core questions was followed by sub-questions:
How did inclusive education emerge?

Who participated in establishing the program? Why?

What personal, political, cultural, and social factors played a part in facilitating this outcome?

How did the various stakeholders cooperate?

What kinds of barriers arose, and how were they addressed?

What successes do stakeholders identify?

What challenges still remain?

What next steps do stakeholders (including educators, parents, administrative officials, and children) identify?

To what extent has the goal of full inclusion for all children been realized? What aspects of inclusion remain to be addressed?

What can be extrapolated as useful for others?

What kinds of international models and channels of financial support were mobilized to realize the project?

What kinds of pedagogic strategies and methods have educators worked out?

How do parents perceive the program?

Goals

What are the goals of the pilot project for inclusive education in Belovodsk? How are these goals described in written documents and articulated by various stakeholders?

The incentives to contribute to the development of inclusive education initiatives in Belovodsk are varied across the numerous professional and personal investments that tie different stakeholders to the project. Yet because a system of education for children with disabilities serves all of these purposes, the singular goal of implementing inclusive education in Belovodsk public schools was able to appeal across a range of motives.

Table 2: Stakeholder Goals

Ministry of Education	Establishing a national education program that meets the highest international standards
International non-governmental partners (USAID, Save the Children, “Step by Step” Community Foundation)	Decreasing institutionalization, increasing social inclusion, and enforcing the right to education for all
Local officials and social workers	Decreasing the burden of poverty for families, spurring outside investment in local community initiatives
Parents of children with disabilities	Creating opportunities for children traditionally excluded; decreasing the stigma that makes raising a child with a disability difficult and socially ostracizing; creating greater social and financial support systems
Teachers and other education professionals	Providing education according to the highest standards, preparing children to live successful lives in society, attracting resources and recognition for their institutions

According to founding documents prepared in cooperation with the Ministry of Education and international partners, the goal of inclusive education initiatives in Kyrgyzstan was to implement a model that would

increase the participation of all children in mainstream schools by:

- changing the education system to better meet the needs of children; and
- improving access to education for children with special needs and from other vulnerable groups in the population, through;
- reform of the education system; and
- wider parent and community participation in education.

[Djumagulova 2004: 7]

Meanwhile, in interviews, local officials and social workers stressed the economic hardship that faces the community, particularly the difficulty of bringing new capital into a community that has had difficulty doing so since the Soviet collapse. If social benefits (financial or otherwise) become available to residents of the region, town social workers are eager to see them used; records in the town are kept as detailed “social passports” for each family, and yearly statistics are compiled and reported to local leaders.

School-based and non-school-based educators discussed a commitment to maintaining a hopeful future for children being raised in a community that has endured difficult changes and economic hardship in their lifetimes. Maintaining the highest educational standards, and the best possible school environment, with the few resources available was high on the list of goals for school directors at all educational institutions visited. The training and resources brought to the school by embracing the inclusive education initiative helped to bolster these goals by providing enrichment for educators that amounted to a symbolic international investment in their work.

Meanwhile, teachers and school psychologists who attended the trainings and participated in the initiative voiced a similar concern for children with disabilities as for all children: that after finishing high school, they have a chance to find a way to earn a living. Considering the social stigma that special-needs children face in their community, several educators remarked that what they would like to do most of all is to create an educational environment for these children so that, despite the social stigma that disability carries in the broader society, they are not burdened by the feeling that they somehow deserve to be ostracized. As the school psychologist at BC3 put it, “What we want to do is to raise these kids without complexes.” For example, she pointed out, many young adults with a hearing impairment would be embarrassed or afraid to interact socially after going to a separate school, and they would never find a job. But that is not the case for those who have been developing alongside their peers all along. Thus the educators seek to raise these children along with their peers, without stigma, so that they can gain the kind of confidence that is necessary for “self-realization.”

The teachers in Belovodsk, whether of Russian, Kyrgyz, or other heritage, consider themselves to be first and foremost post-Soviets. That is, they remain committed to insuring the preservation of a Soviet level of educational success: in spite of the economic and political difficulties facing the country, children should finish school with a strong command

of proper language, of principles of science and mathematics, and a sense of cultural heritage. While much of the cultural richness and stability that they remember from Soviet times has melted away, they have a singular commitment to maintaining standards of education in the face of hardship.⁸ BS3 is particularly devoted to the traditional Soviet educational model. Children wear black-and-white uniforms, help maintain the grounds of the school, and are instructed from the first grade to “sit nicely” at their desks, with arms neatly crossed on the table and backs straight. Children do not wear uniforms at Pervomaiskaia School, but Soviet pedagogy remains the predominant approach. The Soviet educational model is one set of standards that have remained consistent and that the educators have the power to uphold.

Parents of children with disabilities are perhaps most directly concerned with the goal of social and educational inclusion for their children. For them, a greater degree of educational opportunity means a greater degree of freedom for the whole family; a school space that encourages the inclusion of children with special needs emboldens everyone in the family to stop being embarrassed about these differences. It also gives the mothers in particular a greater degree of flexibility—they do not have to choose between institutionalizing or staying at home with that child. There are other options.

Implementation

Kyrgyzstan’s public sphere features a continual interplay of international non-governmental actors, who provide funding for diverse projects, which are then implemented by government employees—local, regional, and federal—who work collectively to implement interventions. Although all of the state employees who were interviewed in the course of this research emphasized how little pay they receive for their respective jobs, they were deeply invested in the structural organization of the state apparatus in order to facilitate the social change that they envision for themselves and future generations of Kyrgyzstani citizens.

⁸ Public school teachers receive a very low salary. In 2010, they received the first pay increase since the Kyrgyz Republic gained independence; this victory was won only through national organizing and strikes. Teacher pay was increased by 30 percent. As a result, a young group of new teachers was attracted to the field, and they were just beginning their teaching careers in the fall of 2011, with mixed results.

Inclusive education in Kyrgyzstan began with joint initiatives from several international NGOs (see Table 3). Investing in the training of Ms. Ailchieva, as a member of the Ministry of Education who had successfully implemented other projects, they sought to build partnerships that would build a new programmatic structure from the top down. Ms. Ailchieva attended seminars on inclusive education in Thailand along with professionals from across Asia. She brought materials and ideas back to Kyrgyzstan. One initiative sponsored the translation of relevant written materials into Russian and Kyrgyz.

Ms. Ailchieva worked with Chinara Djumagulova (a Kyrgyz national with international training) and others to revise the protocol for how disability diagnoses are made and the protocol for subsequent placement of children in schools or institutions. Previously, the diagnostic process was carried out by a commission that met centrally. In 1994, the commission format was reformulated into a consulting committee that includes specialists from education as well as medical professions and works to recognize the input of parents (Djumagulova 2004: 122), although, as in all contexts, when parents and professionals speak of child development, their vocabulary often does not match. Ms. Ailchieva continues to work to establish committees in each province of the country. She also works to bring diagnostic panels and medical and child development experts to more remote areas on a yearly basis to assess children and advise parents and educators.

In Belovodsk, the Ministry of Education partners with local officials, medical professionals, and school personnel to implement the inclusive education initiative.

First, the education officer at the regional administration was invited on board. Parents frequently come to the education office at the regional administration. There, the lone official on duty is able to advise them about the possibility of inclusive education, or institutionalization of children, and schedule children to be evaluated by the committee. Donations of developmental toys from international organizations are kept in a box in her office, to be taken out when the committee meets and used in evaluation. She has two shelves of literature on inclusive education in Russian and Kyrgyz.

Second, directors of local secondary schools were invited to participate. They were then, in turn, encouraged to bring their staff into the fold. Staff were asked to participate in trainings on inclusive education lesson planning techniques and broader goals at schools in the town, which the Ministry of Education orchestrated with support from NGO partners.

Table 3: Institutions Involved in Implementing Inclusive Education in Belovodsk

Name of Institution	Type of Institution	Role of Institution
Belovodsk School Number Three [BS3] [<i>Belovodsk Srednaya Shkola #3</i>]	Public school (grades 1–11, serving ages 7–18)	Inclusive education provider
Pervomaiskaia School [<i>Pervomaiskaia Shkola</i>]	Public school (grades 1–11, serving ages 7–18)	Inclusive education provider
Sunshine Preschool [<i>Detskii Sad “Sol-nochka”</i>]	Public pre-school/ kindergarten (serving ages 3–6)	Inclusive education provider
Belovodsk Children’s Home [<i>Belovodskiy Detskii Dom</i>]	Orphan-age/state children’s home/preschool (serving ages 0–6)	Inclusive education provider for preschool-aged wards of the state (including orphans and children with parents who either relinquished them to state care or whose parents were deemed unfit guardians). The Children’s Home is publicly managed but also receives private donations. Preschool-aged children not only live at the school but receive preschool education and weekly one-on-one instruction with educational specialists. An effort was made as part of the inclusive education initiative to integrate children with developmental delays and physical impairments with their peers in hopes that they will be prepared to attend kindergarten by age 7 (otherwise, they are transferred to a home for children with disabilities, after which their chances for inclusive education are very slim).
Children’s Cultural Center [<i>Detski Obrazovatelnyi Tsentr</i>]	Public after-school and extracurricular education/ children’s library/ pre-school (serving ages 3–18)	The Children’s Cultural Center hosts dance, theater and art classes, houses a preschool that can admit 15 morning students (ages 3–6) and 15 afternoon students, and houses the regional Children’s Library, which has a special initiative with a three-year grant of just over U.S. \$3,000 to support out-of-school inclusion of children with special needs, especially access to computer and Internet skills (the library has three PCs for public use).

The Ministry of Education and Culture of Kyrgyzstan	Government administrative office	As a partner with international organizations in implementing the inclusive education initiative, central workers at the Ministry of Education administer communication with local offices and schools to implement changes to the PMPC [see below], to distribute relevant materials and to plan trainings.
Regional Office of the Ministry of Education and Culture	Government administrative office	As the local face of the Ministry of Education, the regional office receives frontline inquiries from parents and schools about diagnostic process and referral for children with special needs; the regional PMPC is administered by this office, along with numerous other responsibilities. A lone worker, trained as a teacher and psychologist, maintains this post, housed in a small office in a larger regional administration building.
Social Welfare Office at the Municipal Administration [<i>Sots. otdel, Belovodskoe aiyl okhmatu</i>]	Government administrative office	Maintains demographic data regarding the number of children in the municipality who have been diagnosed with a disability by the PMPC; administers relevant disability benefits, including modest monetary pensions to households housing a disabled child.
PMPC [Psychological-Medical-Pedagogical Commission]	Government commission	Administered by the Ministry of Education, the PMPC is a committee of child development experts whose role is to provide consultation to parents and educators about the development of children flagged as potentially having special needs. The PMPC, working as local committees orchestrated by regional offices of the Ministry of Education, seeks to assess children’s needs through organic play in child-centered spaces and, using established guidelines, to recommend a course of action, ranging from inclusive education, to supplemental therapy, to assignment to specialized boarding schools. In some regions, the PMPC also works to educate local leaders about diagnostic markers and inclusive education strategies and to encourage communities to present children who may be at risk for professional evaluation (Djumagulova 2004: 122–126; Ailchieva et al.).
EMIS Project [Education Management Information System]	Public-private coalition project	A collaboration between Save the Children (UK) and the Ministry of Education of Kyrgyzstan (with a sister project in Tajikistan) (Djumagulova 2004: 25–27)

PEAKS Project [Participation, Education and Knowledge Strengthening Project] (2004–2007)	Public-private coalition project	The PEAKS project is envisioned as a coalition that includes separately managed initiatives in Uzbekistan, Tajikistan, and Turkmenistan, as well as Kyrgyzstan, implemented by an NGO consortium in partnership with national ministries of education and local and provincial authorities. In Kyrgyzstan the project seeks “to provide quality education available to all, to build the capacity of teaching staff, develop school curriculum, support wide involvement of parents and other community members in the education process, and to improve school infrastructure” (Djumagulova 2004: 21)
“Step by Step” Community Foundation	NGO	PEAKS Project participant; daughter NGO of the Open Society Foundations Network, which is the sponsoring agency of this case study
Save the Children	NGO	Sponsor for publication of inclusive education policy and description manuals in Russian and Kyrgyz; PEAKS Project and Education Management Information Systems collaborator
USAID	NGO	Participant in PEAKS Project and EMIS project, most notably in Belovodsk, resulting in the publication and dissemination of inclusive education policy and description manuals in Russian and Kyrgyz

Third, the local social work office is on board. Social workers keep the local demographic information; they know which and how many households have children with disabilities, the social conditions in the households, and what government benefits each family is eligible to receive. As the gatekeepers for monetary benefits for children with disabilities, the social workers also become important holders of referral information, directing parents who seek social support to the appropriate diagnostic process, so that they may learn of schooling options.

Fourth, non-school educational institutions are also key players. In Belovodsk, the state residential home for orphans and children without adequate home environments, as well as the local Children’s Cultural Center, have become important contributors. While there is no formal early intervention program, and no universal preschool program in the town, both of these institutions provide expert early childhood education opportunities. At the orphanage, the director works with classroom facilitators to de-

velop curricula for children with special needs, with the hope that when those children reach school age, they can be placed in the orphanage or foster homes and attend school along with their peers, instead of being placed in the home for disabled children, where they will not have the opportunity to be included or develop into participating citizens.

At the Children’s Cultural Center, the preschool program and supplementary programs (including children’s art and dance classes and a children’s library and technology class) accept and support the inclusion of families and children with disabilities. The library has a grant to support access and thus has become an informal meeting place for some mothers of children with disabilities and the children themselves, some of whom attend the nearby Pervomaiskaia School and some of whom study at home.

Thus inclusive education in Belovodsk was established thanks to the cooperation of a diverse array of institutional partners representing local, national, and international levels, and supported by a combination of state funds and international grants.

The complex orchestration of these diverse interests, which has allowed the inclusive education initiative to take root in Belovodsk, is by no means the norm in Kyrgyzstan, where the vast majority of communities have not come together around this issue. Belovodsk represents an exceptional case. From the perspective of the Ministry of Education, Belovodsk was the right choice as a site for the initiative because it:

- had some experience with the inclusion of children with special needs in general education (for instance, before the formal start of the initiative three years prior to this study, some children with special needs had already begun to study at BS3);
- is home to an active regional PMPC, whose members include a defectologist, a psychologist, a speech therapist, a psychiatrist, and an orthopedist;
- the PMPC continues the process of consultation with children with special needs once they have entered the school system;
- has a department of social work in the municipal headquarters that is sufficiently wide-reaching and flexible to contribute to the initiative and is already focused on the support of families and children at risk of social exclusion.

The cooperation of these various stakeholders has allowed those involved in the inclusion initiative in Belovodsk to attend to and address problems

that arose on a local level. The geographical size of the town, as well as its location (as discussed above), therefore has some bearing on the initiative's success. The town is large enough, and sufficiently multiethnic, as well as close enough to the capital city, to support a range of educational and medical professionals. Moreover, these professionals are likely to be loosely acquainted with one another (for instance, the director of the Children's Cultural Center remarked that she had been a member of the *Komsomol* along with the official who oversees the municipal social work office). Yet the town is not so small that professional status is overwhelmed by personal knowledge (as may be the case in small villages). The specialists in Belovodsk, as a rule, regularly engage in professional development, participate in various local and international projects, and are open and receptive to new initiatives and readily adapt them to the local context. As the seat of the regional PMPC, the town has an explicit and ongoing link with the Ministry of Education, giving local specialists direct access to assistance with methodological issues.

From the perspective of parents of children with disabilities, the implementation of the program is thanks largely to the work and openness of educators who were willing to institute new protocols in their institutions and classrooms. The educators have worked to establish conversations with parents of children with special needs, and the directors of the various institutions mobilized their staff members to address emerging issues related to inclusion. In a sense, therefore, the implementation of the program is a testament to these educators' strength of personality and high regard in the community. At the same time, parents observe that while they are extremely grateful to educators, they continue to face a series of barriers to daily attendance.

One parent wrote, in response to our survey, "Now the teachers [at BS3] are more experienced in working with children with disabilities [*deti-invalidi*]. They really approach this issue in the right way. They do everything to ensure that the special-needs [*bolnoi*] child doesn't feel bad about himself, but feels a part of his peer group [*detskoi kollektiv*]." Another parent emphasized the role of the school's director in implementing the program and mobilizing staff to make inclusive education a part of the daily life of the school. This also makes the town a magnet for parents seeking inclusive education for their children.

Tyoma's "Office"

Tyoma is a young boy with mobility impairments who attends Pervomaiskaia School. His mother is herself a former educator. After her husband got a job nearby, she moved the family to the Pervomaiskaia neighborhood of Belovodsk without hesitation when she discovered that the local school director would accept her son. Tyoma also has a younger brother with a similar impairment, so Tyoma's mother strongly felt the need for a public school that would embrace her children, especially because, as an educator herself, she valued education highly and was already aware of Tyoma's above-average intelligence.

Tyoma's mom spoke with the director at Pervomaiskaia School. The director explained that two years earlier, Ministry of Education officials had conducted trainings about inclusive education at the school, and that each year, teachers write a narrative description of children with special needs, and parents write testimonials about progress that become part of the child's school record (in contrast to typical grading practices that do not have a narrative component). Tyoma's mom became more than convinced that this was the right school for him. Tyoma began attending classes and became popular with his peers, who would often come over after school to play video games or read about cars online, since Tyoma's family owned a computer and had an Internet connection.

However, after Tyoma had attended the school for a year, Tyoma's dad's local employment ended, and he began working in Bishkek again. Having already established her children at Pervomaiskaia, however, his mom decided that the family would stay put, in order to preserve a good educational arrangement.

Subsequently, Tyoma had some health complications that made daily transportation to and from school more of a hardship. Previously his older brother had carried him down from the family's second-floor apartment, then retrieved his wheelchair (which the family could not leave in the courtyard for fear it would be stolen). As a result, working with Tyoma's teacher and school director, Tyoma's mom decided that Tyoma could continue his lessons at home. Tyoma spends his days in the family's small apartment, working on his assignments. He sits at a desk in one of the bedrooms that he and his family joke is converted into his "office" during the day. Two afternoons a week, a teacher from the school comes to correct his work, answer his questions, and give him his next assignment. She is paid a modest compensation for this. Because Tyoma is a bright and self-motivated student, he says that he actually enjoys doing his lessons at

home. “If I have a question, I can go online and look it up,” he said. And he still gets visits from his best friends on weekends and in the afternoons. Once or twice a week, Tyoma goes to sit outside in the courtyard with his mother or brother, or they visit the children’s library, where he is popular for his excellent computer skills.

What Does Inclusion Mean in Belovodsk?

What new opportunities for children and families have emerged thanks to the inclusive education initiatives in Belovodsk? What barriers exist? A commitment to inclusive education is evident in the inclusion of children with special needs in the classroom environment, in the thoughtful lesson plans of school teachers, and in the opinions of their peers. The following four illustrations from BS3 and Pervomaiskaia School demonstrate these aspects of effective inclusion.

Dasha’s Math Class

Dasha⁹ is a first-grader at Belovodsk School Number Three. She has moderate hearing loss and wears hearing aids in each ear. Her mother decided to enroll her at Belovodsk School Number Three because she heard that one of the teachers at the school has a son who is deaf, who now, unlike many deaf young adults, now makes a good living working in Bishkek. The teacher, who has the experience of working with her own son, is, as Dasha’s mother suspected, uniquely prepared to integrate Dasha into the standard lesson plans. Not only does she feel capable of catching Dasha’s attention, and noticing when she is getting lost in the course of a lesson, she also, as a parent of a deaf child herself, feels viscerally the importance of Dasha’s inclusion.

One Tuesday morning, Dasha and her peers are seated in tidy rows, two students to each wide desk, facing a chalkboard and bulletin board at the front of the room. A wall of windows along the left-hand side of the classroom casts a late-morning light over the children; it slants through

⁹ Some children here are referred to using pseudonyms. All are called by a first name. All lessons were observed with the permission of school directors and classroom teachers, and full knowledge of the students present. Parents of children who are featured prominently were told about the project verbally by a representative of the school and given the opportunity to request that their child not be included in the study.

the fluffy schoolgirl hair bows and pigtail flyaways with whimsy. Girls and boys rustle papers and open pencil cases to arrange school supplies on desks. They line up a pencil, an eraser, brightly colored counting sticks, and a deck of number cards. Some take care in lining up the counting sticks; others lean over to chatter to neighbors. Dasha is in the front row, at a center desk. Her blond ponytail hangs down to her curved white collar, and from behind, the clear plastic of her hearing aids is visible, nestled snugly behind each ear.

The teacher enters briskly and energetically. She has close-cropped hair and is dressed in slacks and a smart knit blouse. Crossing the front of the room, she stands facing the children and greets them boldly, with broad arm motions and a lilting voice. Let’s say our rhyme, she instructs, and the children echo each line in turn of a stanza encouraging excellent posture for proper studying. As the rhyme concludes, she smiles out at her now-attentively poised group of six-year-olds. “We are going to learn how to answer the question ‘how many?’ today!” she asserts encouragingly. “What are we talking about today, children?” she asks, then repeats the topic.

She launches into a lesson that, as promised, is focused on how to consider and address the question “How many?” Rehearsing different ways to word the question, various ways of counting, adding, and subtracting, and providing examples with various countable objects, she urges the children to make a conceptual connection about what is meant by the question itself. Moving every two minutes to a new example, she goes from small cartoon animals velcroed to the board, to magnet cars, to number figures arranged in a row over the board. She watches over her classroom as she moves swiftly back and forth across her space at the front, gesturing to children whose gaze has wandered toward the window or a hangnail or sleeve cuff. Frequently she directs questions toward the children. “Two cars and two more cars—how many cars are there now?” she asks, and then calls a child’s name.

“Dasha,” she asks, moving in front of Dasha’s desk. Dasha looks up at her. Making eye contact with Dasha, she covers her own mouth with her hand and repeats the question. “One car has driven away. How many cars are there?” Dasha’s face is turned upward attentively toward the teacher, but she remains silent. The teacher repeats the question, her lips hidden, forcing Dasha to rely on her hearing to understand the question. Dasha answers, slowly, but with growing confidence. Sometimes her arithmetic is off by one, but she is always reassuringly redirected and arrives at the correct answer. Dasha’s peers seem to give no thought to the way the

teacher addresses Dasha, paying the same attention as they would when she directs questions to anyone else.

Ksenya's Literature Class

Ksenya, a young girl with intellectual delays, was in the fifth grade at Belovodsk School Number Three in 2009. On one particular day, her literature class was practicing identifying place names in a literary text. The teacher explained the new material and objectives to the class. As others began the assignment, Ksenya called for individual help to understand instructions for the simplified materials the teacher had prepared for her. Ksenya did this work in the same time period, during which the rest of the class did the general assignment. When the class reviewed the main assignment as a group, Ksenya followed along with the more difficult materials.

Then the teacher divided the class into groups, and every group was given its own text in which to find place names—with the instruction to compete to see who could finish first. Ksenya was assigned an easier text. She correctly located the place names in her text. Then a few students were directed to write the names of the places on the board, while the rest recorded the place names in notebooks, along with comments. Ksenya copied the words into her own notebook but then struggled to compose comments about the places mentioned. The teacher, who had placed Ksenya's desk close to her own, quietly asked her to give concrete examples from her life. She helped her by breaking the work into smaller steps.

All of these efforts resulted in Ksenya's incorporation into the lesson and participation in the class along with her peers.

Inclusion and Continuing Challenges, Case by Case

Based on these examples, academic inclusion for children with a range of special needs is well underway in BC3 and Pervomaiskaia Schools. In addition, both schools have worked to renovate their physical facilities to make them more accessible. This has primarily meant adding ramps to main entrance ways and creating usable indoor toilets available to students (instead of existing outhouses). These examples show that the educational practitioners are working to adapt the educational system to children who were previously excluded.

However, there are still several categories of children who are excluded from educational opportunities. These include children with severe

and multiple disabilities (who are still deemed uneducable based on PMPC policy); children whose parents are unaware of the inclusion initiative and/or still deterred from sending their children to school by social stigma; and young children whose parents do not recognize their special needs in time for them to be diagnosed and prepared to enter first grade with their peers.

These categories of need suggest the need for interrelated solutions. Ableism persists and must continue to be addressed in educational policy and curriculum (Hehir 2005) geared toward the eventual possibility of inclusion of all children in schools by adapting schools rather than children. An umbrella parent organization should be established that also partners with regional groups and conducts broader public awareness campaigns to supplement the top-down initiative with greater responsiveness to bottom-up needs. Finally, early intervention services must be developed and implemented and public preschool and kindergarten programs bolstered (in both quality and quantity) to prepare all children for school.

Access, Infrastructure, and Staffing

Physical accessibility remains a challenge, with four major arenas of physical access highlighted in conversations with stakeholders: transportation, school facilities, classroom facilitation, and access to nursing care in schools.

At the Belovodsk School No. 3 parents’ meeting, several parents expressed concern over how their children get to school each day. For instance, Natasha’s mother explained that in the winter, when there is snow and ice on the ground, the half-mile walk from their home to the school becomes a hardship for Natasha, who sometimes stays home if there is no way for her to get a ride to school. Other parents who were present nodded in agreement—walking to school can be dangerous for children with sensory impairments as well, and many families do not have access to a car. One possible direction for future improvement of the inclusive education initiative would be for parents, along with other local stakeholders, to arrange for a bus to bring children with special needs to their respective schools. A similar initiative, in which parents obtained funding to purchase a bus and pay a driver, was recently successful in Petrozavodsk, Russia (Hartblay 2012).

The realities of educational funding and infrastructure in Kyrgyzstan present barriers to inclusion as well as to quality education in general. The director of Pervomaiskaia School listed several ongoing difficulties facing

inclusion at her school. First, the physical space of the school is in need of repair; because the building is much older than other buildings in the region, simple maintenance repairs tend to take up all of the yearly maintenance budget (each school in the district is allotted just under U.S. \$500 per year [19,000 som] for renovations). While other schools have enough money left over after repainting and fixing leaky windows to purchase new furniture or improve the heating system, Pervomaiskaia spends all of the yearly budget on repairs and is visibly poorer than its neighbors. This inhibits the director's ability to increase accessibility incrementally, and so she is currently seeking grants to either renovate the building more thoroughly or move to a new building entirely.

Second, several of the children with physical disabilities at her school need a great deal of extra physical help. Because there is no budget to pay facilitators to aid children in the classroom, two mothers come to school with their children each day. But not all families can send a parent to assist a child, so the school is limited in its capacity to offer inclusive education to all children. It is partially for this reason that Tyoma's education has been changed to a "distance" plan in which he studies from home. With an increasing number of students who have behavioral difficulties, like hyperactivity, classroom teachers are stretched to maintain lessons. Finding a way to add a facilitator to the budget to attend to special-needs children who need assistance would also improve accessibility. Creating a training program in which older students could earn recognition for becoming classroom assistants for younger students would also help in this regard.

Finally, there is no nurse on staff at the school, which again means that children who require higher levels of care either need a parent to come to school with them or must study from home.

Support for Teachers

An additional manner in which accessibility could be sustained in classrooms at all institutions in Belovodsk would be to create an ongoing program of seminars or retreats for educators to discuss special-education needs and practices. All educators interviewed for this case study cited the pilot program's initial round of seminars on special education as a great success and an excellent professional development opportunity for teachers and administrators alike. A low-budget program that continued to bring together local educators to discuss topics in special education, perhaps semi-annually, would be well-attended and well-received. It would

also facilitate further discussion around the barriers related thus far and would help teachers to extend their practices of accessible pedagogy by creating a space to share strategies for addressing particular problems like adapting lessons for children with poor handwriting, adapting lessons for children with learning disabilities, targeting lesson plans to minimize disruption from children with behavioral problems, and so on.

Because the groundwork of basic inclusive education principles and vocabulary has already been laid, the need for outside experts has decreased, and such a program could be administered locally, with a modest honorarium for organizers. Furthermore, such a series would help to bring new and younger teachers on board and up-to-speed with the initiative (which is particularly a concern considering that, due to the recent salary increase, more new teachers joined the school staff in 2010 than in any other year in recent memory).

Parents and Community Acceptance

The inclusive education initiative in Belovodsk has achieved varying levels of success in changing broader attitudes about disability. Surveys conducted by Ms. Ailchieva and by the school psychologist at BC3 indicate that students at the school 1) are aware of the principles of inclusive education and 2) accept their peers with disabilities wholeheartedly. For instance, children in Natasha’s class responded to written instructions to list other children whom they would like to invite to a party, or trade presents with, and Natasha was one of the most popular classmates.

At the same time, parent feedback collected in interviews and surveys indicates that attitudes in the broader community continue to present challenges and limitations. For instance, the mother of Tyoma (a student at Pervomaiskaia School who studies from home and uses a wheelchair) recalled numerous times when she or her son received verbal abuse from passersby on the street. Many people assume, she pointed out, that because Tyoma uses a wheelchair, he is also intellectually limited—so strangers tend to think that they can say things about him and he will not understand. Tyoma himself is well aware of the ignorance of his fellow citizens about disability, and he says that he would like to be a disability activist when he finishes school.

At the same time, parents of children with a diverse range of special needs—and with very different personalities—may actually find it difficult to talk to one another. For instance, in a meeting with parents at BS3, the common ground between the needs of children with cerebral palsy,

visual impairments, and hearing impairments was not immediately obvious. The presence of a researcher presenting interview questions acted as a facilitating influence, and after 40 minutes, the parents began to voice commonalities. This evidence indicates that there has yet to be a comprehensive effort to support the development of a strong and centralized parent organization in the town. Another issue that parents and teachers alike report is a concern for the fate of special-needs children when they finish school. Jobs are already scarce, they point out. Who, they wonder, will hire someone who walks with a limp and has poor handwriting, when there are already too many overqualified young people for available good jobs?

Conclusion

Inclusive lessons like those detailed above are implemented every day in Belovodsk and, thanks to the cooperative engagement of a diverse range of stakeholders, facilitate the realization of important social possibilities. As a result, children with special needs and their family members benefit: the children have the opportunity to become active members of their community, to become social beings “without complexes,” giving parents hope for their children’s future. And all of the children in the class develop a sense of responsibility for the collective and a sense of interdependency. The children who do not have developmental or sensory impairments learn about the problems of children with special needs and begin to attend to and to understand these children, to value them as classmates, and to value their right to equal participation in social life. Such inclusion erodes barriers between children; in this way, inclusive education eventually leads to an inclusive society.

Yet the implementation of education for *all children* in Belovodsk has yet to be realized. According to the PMPC policy, children with Down’s syndrome, those with multiple disabilities, and others are still excluded from the opportunity to attend school. On the one hand, the promise of an inclusive education program means that within a generation, the kinds of social attitudes that prevent such children from being included will tend toward acceptance. On the other hand, this means that a generation of citizens will languish in institutions or what amounts to incarceration in family homes without opportunities for self-realization or participation in society. Inclusive education will not save this generation of children; in order to do so, a simultaneous, broad-based popular awareness campaign

to alter public opinion toward accepting and valuing difference would be necessary. Moreover, a public awareness campaign would do much to improve school attendance of children with disabilities (by informing parents of the opportunity and reducing the stigma of public “coming out” as having a disabled child), the possibilities for employment for adults with disabilities (by urging and creating incentives for business owners to employ disabled workers) (for an example from Ukraine, see Phillips 2011, Petryna 2002), and otherwise facilitate inclusion by addressing negative attitudes in the adult population in much the way that teacher attitudes have been changed through the inclusive education initiative. Although orchestrating such a program from the top down would be costly, empowering and mobilizing parents to take on this issue would both align with original project goals and help meet the “top down” from the “bottom up.” Ultimately, attention to this chicken-or-egg problem reminds us that the goal of inclusive education is not only to raise children without complexes but also to create a society that is itself free of complexes about difference.

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Community-based Services in Kyrgyzstan: Umut Nadezhda Rehabilitation Center

Anastasia Kokina and Nina Bagdasarova

The school day at Umut Nadezhda Rehabilitation Center for students with severe and multiple disabilities begins as children arrive and get off the school van. Teachers, teacher assistants, and volunteers put on their coats (the temperatures are below freezing) and walk outside to greet the children and assist them into the building. Some children walk independently, others use wheelchairs and are helped by their peers, and yet others are carried by adults. Younger children are hugged and kissed; a teenage girl exchanges a kiss on the cheek with a volunteer almost her own age; two adolescent boys in hooded sweatshirts greet each other with a handshake. There are giggles and joking around. After jackets are hung and boots are changed for house slippers, the children enter the room that serves as the assembly hall. Some children who live in a residential program are already there, playing on their own or with their peers. It's warm inside, and the curtains let through the winter sunlight. A girl in a wheelchair is playing piano. After some transitional hassle, the children get in the general morning circle, a daily ritual that is zealously followed by everyone at Umut and its sister organizations. The ritual begins with a student, a different one each day, lighting a candle placed on a table featuring an installation that symbolizes the current season. Now it is winter, represented by pine-tree branches, silver glitter, and white cotton for snow. Perizat,* a middle-school teacher, plays a flute while everyone is absolutely quiet; the opening song, "Good Morning," is followed by a sequence of other songs, verses, and games. Teacher aides assist the students with physical

* Names have been changed to ensure confidentiality, unless otherwise permitted by participants.

movements or by otherwise promoting their meaningful participation in each activity.

Asan, a boy with Down's syndrome, is sitting on the floor with his hands wrapped around his body, tears in his eyes, unhappy about something, and refusing to participate in the activity. When it is his turn to imitate the rhythm played with drumsticks, everyone waits for him; nobody rushes to physically redirect or prompt him. About a minute passes. When Asan finally does what is expected, enthusiastic cheers and applause follows from everyone. A smile appears on the boy's face. The school day is going at full speed.

The Case Study Method

The main goal of the case study was to document ways and challenges of working with children with disabilities in Umut Nadezhda Rehabilitative Center in Bishkek, Kyrgyzstan. To accomplish this goal, the case study sought answers to the following research questions.

1. What is the history of Umut Nadezhda Center? Why and under what circumstances was it created, and who were the people involved?
2. What methods and approaches to education and rehabilitation of children with disabilities are used at the Center? What modifications and accommodations are made for individual students to facilitate their learning?
3. What is being done to facilitate inclusion of students with disabilities in the local community and/or system of formal education?
4. What is the process of teachers' professional development?
5. How do key players (such as teachers, parents, and volunteers) collaborate with each other and with outside agencies, organizations, and the community?
6. What are the barriers for inclusion and service delivery?
7. What makes the Center unique?

A case study methodology (Yin 2008, Stake 1995) was selected as appropriate for addressing the questions above. Several methods of data collection were used to achieve data triangulation, including individual and focus group interviews, observations, permanent product analysis, and documentation reviews.

Interviews were conducted with multiple informants, including the administration of the Center, teachers, related specialists (such as occupational therapists), volunteers, parents, and students. Interviews were conducted individually or in a focus group format, depending on informants' preference and availability. As a result, a total of 14 individuals were interviewed. The interviews were audio-recorded, with participants' consent. The interviews covered the following broad areas: (a) interviewees' roles and involvement with the Center and any background information, (b) what the interviewees like about the Center, (c) what, in their opinion, makes the Center unique and/or effective, (d) specific methods and approaches used to address social, behavioral, academic, and emotional outcomes, (e) challenges and suggestions for improvement, and (f) plans and hopes for the future of students at the Center. Although those general areas were covered in all interviews, specific questions were modified for specific stakeholder groups to fit their individual abilities and/or situations (such as simplified content in student interviews and more specific questions about methodology of teaching in teacher interviews). Follow-up questions were asked to expand on any topics of interest. All interviews concluded with an open-ended question ("Is there anything else that you would like to tell us that we have not discussed so far?").

Observations were conducted in multiple settings and programs of the Center, including preschool and school programs, classrooms and hallways, dormitories, playgrounds, and workshops for adolescents and young adults. Observations were loosely structured but focused on the following aspects: (a) interactions and relationships between stakeholders (such as teacher-student and student-student relations); (b) characteristics of the physical environment, (c) evidence of collaboration between stakeholders, (d) strategies and methods used inside and outside classrooms for social, emotional, behavioral, and academic development, (e) the use of differentiated instruction to fit the individual needs of students.

The analysis of documentation and the permanent product review were conducted using the following sources: the Web site of the Center, policy documents, informational materials including press releases and journal articles, training materials, students' individualized educational plans, and teachers' training portfolios and lesson plans. In addition, photo and video documentation was conducted, with stakeholders' permission, to provide illustrative points to the narrative. Data collection was conducted within a period of 10 days in December 2011, in Bishkek, Kyrgyzstan. Two case study researchers conducted all interviews and observations together. To analyze the data, interviews were tran-

scribed, translated into English, and coded into recurrent themes, which provided structure for the present report.

History of the Center

Founded in 1989, in the tumultuous years just before and just after the collapse of the USSR, Umut Nadezhda Center was one of the first organizations in the region to provide education and rehabilitative services to children and adolescents with severe and multiple disabilities.¹ Previously, children with significant disabilities were deemed “unteachable” and denied any access to education. In the past, many parents of children with disabilities were forced to give away their newborns to state institutions, where some of them died because of inadequate care. Karla-Maria and Igor Schalike, a married couple who founded the Center, were deeply affected by stories of Kyrgyz women who were forced to abandon their children with disabilities. Shortly after losing their own child, the Schalikes decided to dedicate their lives to helping families of children with disabilities.

The path toward creating what is now known as Umut Nadezhda Center was turbulent. After the collapse of the USSR, state funding for the Center was discontinued. This was followed by a series of other mishaps, including the loss of a newly renovated building, several forced evacuations from rented apartments, and harassment from the local community. The fact that Ms. Schalike was a German citizen also led authorities to view the Center’s activities with suspicion. Many administrators and community members could not understand the motives of a person who abandoned a comfortable life and family in a Western country and came to live in a poor country in transition. Today, the personal efforts of Karla-Maria and Igor Schalike in creating an effective model of service provision and transition have been recognized nationally and internationally. Ms. Schalike’s long list of awards includes a nomination for the Alternative Nobel Prize project, “1000 Women for Peace,” the Order of Merit of the Federal Republic of Germany, and the Danaker Order of the Kyrgyz Republic.

¹ Children with severe disabilities have a significant degree of cognitive impairment, which may be combined with other conditions that significantly affect their learning and participation in daily activities (such as orthopedic disability, hearing/vision disability, or behavior disorders). Children with multiple disabilities usually have a combination of any of the above conditions.

The Center has grown and expanded. With the assistance of several international organizations such as the Soros Foundation and UNICEF, it has acquired its own building. However, it continues to exist completely outside the formal education system. Comments from key personnel indicate their lack of reliance on or hope for support from the government. In fact, Mr. Schalike notes, the Center was created in response to a lack of state-funded services for students with disabilities:

In a way, the system of supports that you see now as part of Umut Nadezhda was built around our students and was driven by their needs. First, we organized a preschool and school groups. Then, as our children grew, we created transitional classrooms for them. When our teens became young adults, we organized workshops. Our new project is to create a ‘social village’—a community for adults with disabilities with a farm, garden, and workshops. It would provide them with food and employment; they would take care of themselves and each other. It will be a place where people can live a decent life independently. You have no chances in this world if you cannot help yourself.

In addition to being a pioneer in providing educational and rehabilitative services to children with severe and/or multiple disabilities, Umut Nadezhda was one of the first organizations in the country to implement inclusive education. The inclusive classroom followed the “reverse inclusion model” in which students without disabilities, typically children of staff members or their friends, were included in the group of children with disabilities. Unfortunately the classroom is not in place anymore, as the students grew up and graduated from Umut. Three out of 10 students with disabilities from the original “inclusive cohort” went on to pursue higher secondary education. Many others are living independent lives, and some have productive employment in a country with a high incidence of unemployment and labor migration. Several graduates have become advocates for other individuals with disabilities, having founded community organizations and support groups for families and individuals with disabilities.

Country Context

Kyrgyzstan is a small country located in the middle of Central Asia. About 5 million people live in the country, about 30 percent of whom are under 15 years old. The population includes more than 80 ethnic groups, the largest being Kyrgyz, Uzbeks, and Russians (OECD 2009). A former Soviet republic, Kyrgyzstan obtained independence in 1991. Then began the process of democratic transformations and reforms. Despite the many

accomplishments made through the recent institutional reforms, numerous problems remain; the main ones are the low level of economic development and high poverty. In addition, in 2005 and 2010, respectively, the country was shaken by two serious political crises, accompanied by significant ethnic violence, which resulted in a change of government. Subsequently there were significant reductions in social welfare, health care, and education. Inadequate funding leads to a lack of services for students with and without disabilities, a dearth of up-to-date textbooks and educational materials, and an insufficient number of highly qualified teachers. The sobering consequences are school failure and high dropout rates, particularly in rural areas. The results of the PISA survey (Programme for International Student Assessment) (OECD 2009) illustrate Kyrgyzstan's extremely low academic performance; its scores were the lowest of all participating countries.

Education in Kyrgyzstan is compulsory for children between the ages of seven and 15, but only 14 percent of younger children (zero to six years old) have access to preschool education (GMR 2011). Transition-age youth have the option of staying in high school or graduating and enrolling in professional or vocational education. The Kyrgyz constitution guarantees every child the right to an education. However, discrimination on the basis of disability is never specifically mentioned (OECD 2009). Two additional laws, the Law on the Rights and Guarantees of Persons with Disabilities (April 2008) and the Law of Education, assume that some children with disabilities may be uneducable and promote separation of those children from the general system of education. Implementation of national legislation with regard to access to education is not always adequately monitored; for example, schools are not being held accountable for their failure to provide education to students with disabilities (OECD 2009). Furthermore, the reliance of the traditional deficit-based model of special education, originating in the writings of Vygotsky (the approach he called "defectology"), creates another barrier to inclusive education. The dominance of defectology over time saw the emergence of separate professional identities, expertise, and roles for those educators trained as defectologists, who often carried out their work in segregated institutions. This separation of professionals and the segregation of children led to negative views of disability and continues to be a barrier to inclusion.

Education for children with special needs is further hindered by the fragmented and inadequate system of funding and service provision, a lack of an effective identification/child finding system, and outdated assessment and diagnostic tools. A lack of state funding of special schools,

where children are typically grouped by disability type (such as vision impairment or intellectual disability), results in dependence on parental fees and donations from sponsors (OECD 2009). Finally, schools under the jurisdiction of the Ministry of Education or the Ministry of Labor and Social Protection have to operate within the boundaries of the norms and curricula provided at the national level. Hence there is a lack of differentiation and flexibility in adapting teaching and intervention approaches. All this makes state-funded special schools inaccessible physically, pedagogically, and financially to many families, particularly those from the distant rural areas.

Several important steps are under way to improve the situation, including a reform of teachers' wages, which resulted in the improved staffing in rural areas. Curriculum reform aimed at redesigning the school curriculum to focus on key general competencies common across all content areas (such as social communication, problem-solving, self-regulation, and handling information) might also help. The use of the new competency-based curriculum may lead to a higher degree of inclusion through greater flexibility and differentiation of instruction for children with special needs.

Furthermore, the difficult situation with the education of children with disabilities has stimulated many initiatives from international and local non-governmental organizations (NGOs), including efforts to improve health conditions, teacher training, occupational therapy, and rehabilitation. Inclusion is one of the priorities of international organizations working to improve education in the region. To accomplish this goal, work is being done to change societal attitudes and to promote disability awareness, provide professional training, and increase the quality of education and related services. Though recent reforms and initiatives are promising, additional efforts are still required to improve the quality of education and inclusion of students with special needs in Kyrgyzstan.

The Center Today

Today, Umut Nadezhda remains one of the few organizations to provide specialized services to students with disabilities and to serve all students regardless the complexity of their condition. The Bishkek campus currently provides education to 58 children, adolescents, and young adults, ages three to 27. Many students have multiple support needs and require intensive care and treatment, including physical rehabilitation and medical

supervision, as well as carefully planned educational and behavioral interventions. Specific diagnoses include orthopedic disabilities (such as cerebral palsy), developmental disabilities (including autism and Down's syndrome), severe intellectual disability, or visual impairment. According to recent data, 43 percent of the student population has an orthopedic impairment, 38 percent have various degrees of intellectual disability, and 19 percent have a combination of the above.

The student population has been changing in recent years; there are now more students than ever with intensive physical, emotional, and behavioral needs. This may be a consequence of improved societal attitudes and educational opportunities available for those children. In the past, parents of children with significant degrees of disability had no hope for education and therefore did not seek educational opportunities for them. Today, more parents have become advocates for their children. Many have actively sought educational opportunities for their children and have succeeded in getting them included in regular education. Consequently, the changes in schools require additional training, the refinement of intervention approaches, and new strategies by the administration and teachers.

Umut Nadezhda is a non-profit organization that currently receives no funding from the national government. About one-third of funding comes from parents; the rest is provided through private donations, mainly raised in Germany, and by grants from international non-profit organizations. The Center currently functions as a network of independent programs, including a preschool classroom, four school-age groups (first, fourth, and seventh grades, and a classroom for transition-age youth, grades eight and up), and the Janusz Korczak Vocational Center for adults with disabilities. There are two residential programs on the Center's Bishkek campus, hosting a total of 21 children, that provide housing for children from geographically distant areas and also for orphans.

The recent restructuring of the Center's administrative model led to an abandonment of the traditional top-down organizational approach, in which the administration of the Center was responsible for coordination and management of service provision. Now, a board of trustees consisting of parents, the administration, and teachers collectively makes the most important decisions and coordinates services. The main function of the Center's administration is international fundraising, communications, coordination of services, professional development, and case supervision. Everything else, from domestic fundraising and housekeeping to purchasing supplies and educational programming, is the responsibility of each individual program, coordinated by lead teachers.

The Center utilizes a highly individualized child-centered approach, based on the humanistic principles of Waldorf education. Services include educational interventions, physical and occupational therapy, hippotherapy,² massage, and on-site consultations by a licensed psychiatrist. In addition to core academic subjects (such as reading, math, and science), music, dance, cooking, and arts and crafts constitute a substantial part of the school day. Students stay as a group with one teacher from elementary to middle school.

Waldorf education was founded in the 20th century by the Austrian philosopher and educator Rudolf Steiner (hence its other name, Steiner's education). Humanistic views of human development and education, based on the belief that freedom is an essential right and inherent desire of every individual, form the foundation of this approach. According to Steiner, all children have the right to grow and develop, and the goal of education is to assist them in realizing their potential. Recognizing the value of every child as a "world citizen" and a "member of humanity" (Provenzo 2009), teachers must create a classroom environment that inspires students' exploration of their environment, creativity, and independence. Human personality is viewed holistically, as a combination of physical, social, intellectual, and spiritual domains. Therefore, the goal of education is not only the acquisition of skills and knowledge but also assistance in the formation of the various aspects of students' personalities. Waldorf's theory also views child development as a sequence of three seven-year stages, each associated with the emergence and development of specific characteristics and skills that impact learning. For example, preschool children learn through imitation, imagination, play, and sensory experiences (Edwards 2002).

As a result, the formation of skills and characteristics should come at certain times, and skills should not be "forced" unless the child is "ready." For example, the teaching of reading and writing does not begin until the elementary stage (seven years and older); younger children interact through storytelling, play, and oral language. Teachers also foster creativity, artistic expression, and imagination and extensively use hands-on activities, arts, crafts, and theater. Eurythmia (the

² Also called Equine Assisted Therapy, hippotherapy uses horses to provide sensory and motor input as part of a therapeutic program for people with physical and intellectual disabilities.

art of movement) is taught through daily physical exercises and rhythmic games, which improve children's use and awareness of their body and their physical environment. The system of rhythms (daily, weekly, and annual) is also implemented through the cyclical repetition of everyday activities and seasonal festivals. Additional components of the approach include: (a) teachers working with the same group of children for several years (traditionally, between the first and eighth grades); (b) teaching conducted in "periods of study" or "blocks" with focused concentration on a certain academic area over an extended period of time, in which connections are made between the school subjects; (c) the use of natural materials and partial rejection of modern technology, especially with younger children; (d) the use of collaborative learning, particularly in secondary grades; (e) rejection of standard methods of evaluation and assessment (unless mandated by the government), such as standardized tests and grades; (f) encouragement of teacher autonomy, creativity, and personal growth (Oberski 2009). While the model was initially developed for children without disabilities, it may be used in educating children with special needs (Damovska 2005). Although evidence on the effectiveness of the approach has been mixed (Provenzo 2009) and the number of studies examining outcomes specific to students with disabilities is limited, the number of Waldorf schools is growing; currently there are over 1,000 schools in 60 countries.

Physical Environment

The main campus of Umut Nadezhda is located in a small neighborhood on the outskirts of Bishkek. The neighborhood is quite difficult to access using public transportation, and the road that leads to the Center is in need of repair, like many roads in Central Asia. The Center is gated, and one needs to use the gate buzzer to enter the premises. Inside, however, it is striking how, given the limited financial resources and, at times, less than ergonomic environment, the space feels like home. The school building is accessible, and several wheelchairs are parked by the entrance. Hallways are decorated with students' photographs, drawings, and bright handmade posters. The walls of the classrooms are painted in warm colors—peach, pink, and orange. Children's drawings and work samples are displayed on the classroom walls and on wooden shelves. In some classrooms (for instance, in the preschool), posters provide an illustrated summary of the

main aspects of each child's individual program (such as goals for motor development with recommendations for exercise). Every classroom has student desks of appropriate size, a separate space for naptime (mats or sofas), space for play and for younger children, and a child-size house. Children can play with a variety of toys, books, and exercise equipment (such as gym balls) and draw with colored pencils and crayons. As in many Waldorf schools, natural materials are favored, such as clay and natural wood. Every classroom is staffed by one lead teacher, together with teaching assistants, student teachers (interns from local colleges) and volunteers (typically, trained social workers from Germany). The student-to-teacher ratio varies depending on the grade level and the degree of individual students' need, but it typically ranges from about two-to-one in classrooms with younger students, to three-to-one in secondary grades.

Next, findings pertaining to common themes discussed by interviewees will be discussed in more detail. Those themes include program philosophy, methods and approaches, the training model, and collaboration. Finally, current challenges, hopes, and dreams discussed by participants will be described. The themes will be illustrated by the participants' quotes.

Program Philosophy

One of the common themes raised by most teachers, specialists, administrators, and parents concerned the various aspects of program philosophy—a set of underlying beliefs shared by all stakeholders that guide their everyday efforts. The foundation of Umut's philosophy is its *inclusiveness*, or the belief that that no child should be denied access to services, regardless of the extent of his or her disability. Indeed, there are no specific criteria for admittance to the Center, and children with any degree of disability are welcome.

No one is excluded, regardless of their difficulties. Some children have more challenges than others, some cannot walk, others can only lie down, some may have intellectual disabilities. Nobody is denied education, and they [specialists] are able to work with children who are different. (parent)

As a result, Umut Nadezhda remains one of the few organizations in the country that provides educational and rehabilitative services to students with the most severe disabilities. This presents specialists with the challenge of providing individualized instruction to students with diverse needs and abilities in one classroom. However, having an environment

where students with mixed ability learn together is instrumental in providing them with positive models of peer behavior, and in promoting collaboration as children assist each other in their respective areas of difficulty.

Another aspect of Umut's philosophy, derived from Waldorf education, is genuine *respect* for students' dignity and the underlying assumption that every child should be treated as an individual capable of realizing his or her potential. Specialists and parents learn to respect students' preferences, interests, and desires and to follow the student's lead; this often helps them in identifying students' specific strengths and promotes student's self-determination.

We need to accept our children the way they are. It is important not to force them to do things but assist them where and when they need it. A child can reject my suggestions—and has every right to do so. I respect it. We also train specialists to respect themselves and to grow. You teach them that [although] they may make mistakes, they will still be accepted and not judged. (administrator)

There is no place for pity. You only assist a child as much as he allows you. If you have an agenda of your own, your set of methods, and are telling the child 'I want you to do this or that,' it is not going to work. You should not focus on what you want the child to do but rather understand the child's needs and desires—only then can you help. Too much assistance can cause students to be helpless and dependent. (teacher)

Each of us can choose what to do. Everyone follows their own interests. If you are interested, you can polish wood. If you are not, [you can] do something else. (student in the vocational center)

Furthermore, Umut Nadezhda's approach to education is *strength-based*. The focus on what a child is good at rather than on his or her shortcomings or difficulties is crucial and makes the program different from the traditional deficit-oriented approaches, in which student shortcomings are identified first and then specific ways of treatment are prescribed to match those shortcomings. In Umut's model, students' strengths are identified before their needs and constantly fostered.

The major focus is to have teachers realize that every child is, first of all, an individual, and that his individuality has full value; then observe the child, get to know him, focus on what a child can do, on his strengths. We never begin with what a child cannot do. (administrator)

A related theme can be defined as *equal opportunities* or *individualized approaches*. This is a shared belief, emphasized through everyday work and weekly training, that students with disabilities deserve to be provided with the same education and opportunity for inclusion as students without disabilities. At the same time, as each student has a unique personality,

abilities, wants, and needs, approaches to education should be individualized. Some students should be provided with additional supports to benefit from their education.

Before I thought that children with disabilities had to be separated. Now I believe that we are all equal. Children with disabilities have the same rights and should be together with others. We are all different. We are all people. One needs to find strengths in any child. Our goal is to educate all children, but individual characteristics and ways are different. (teacher)

Making It Happen

A second broad group of themes discussed by the stakeholders pertained to the specific approaches and methods of service delivery. The crucial first step towards implementation is getting to know the student. All incoming specialists are required to attend a number of training sessions aimed at getting them familiar with their future students' individual needs prior to meeting them personally. These seminars are intensive and include the discussion of philosophical foundations of education, the introduction of methods and approaches, and the discussion of specific disability types and student cases. This gradual approach of introduction of teachers to the classrooms is important, as some novice teachers may not be ready for the challenge of meeting their future students. Moreover, increased awareness of students' individual differences helps teachers to fine-tune their strategies and tailor them to the needs of students and facilitates positive teacher-student relationships. The gradual approach is also beneficial for students, as some of them may get overwhelmed by the arrival of new individuals.

Once you get to know the student, it's a big step. The child opens up. We want to show them that the world is not such a bad place. (teacher)

Improved knowledge of individual differences and understanding is an important step towards empathy and acceptance, not only in school settings but also at home with parents and with typically developing peers.

Before [the training at the Center], I treated my child as any mother would. I did not understand him completely; I sometimes spanked him. Here, I learned to treat him with respect. He needs to discover the world. His vision is bad, so he needs to touch everything. Recently, he poured water from a tank all over himself and everywhere around him. Before, I would punish him for that, but now I see things the way he sees them—he is on the floor, wet, scared. I felt so bad for him. Sometimes, as a parent you may lose your temper, but working with those children, you learn how to control your emotions. You need to be really patient. (parent)

Everyone's first reaction is shock, but if a person is well informed, everything makes sense. I remember how fast I adapted. We became close friends, we learned about [peers with disabilities], that they were just like us. You just need a bit of time. Now I do not see those differences anymore—you just get used to it. It was not a problem to do it. We joked around and played. Anna has a difficult form of cerebral palsy, but we learned her gestures, the way she communicates. (graduate of the Center without disabilities who attended an inclusive classroom)

Recognition of, and respect for, students' diverse backgrounds, individual strengths, learning styles, and interests are intrinsically related to individualized differentiated instruction—another key component of the Umut model.

Individualized planning immediately follows the “getting to know you” stage. At the beginning of each year, lead teachers, in collaboration with colleagues, initiate an individualized educational plan for each student. Individualized plans begin with a general description of the student's development and history and an evaluation of their motor, intellectual, and social development. Consistent with developmental theory, estimates in years are provided for each skill area in reference to typical child development (e.g., a student's actual age may be seven, but his language development may be at age two). Additional information on file may include teacher's notes about individual student characteristics as well as information on approaches for children with specific disabilities (like autism) or behaviors (such as addressing aggression). The goals targeted in individual educational plans may address motor skills, life skills, pre-academic skills such as shape and form identification, and following instructions. Each month, teachers collect data on select developmental or educational areas. For example, a simple data collection sheet may include columns with specific skills (such as using a spoon to eat) and an indication of whether the goal was met in the given month. A method known in Western literature as “task analysis” is used to teach complex tasks such as hand-washing. As part of this method, long tasks are broken down into simpler components, which are then taught one step at a time (for instance, hand-washing is divided into “turn on the faucet,” “get hands wet,” “put soap on hands,” and so on). This approach increases the probability of success and facilitates skill mastery.

Every child has an individual plan—his history, characteristics, motor skills, emotional development, and a treatment plan. Now we include annual plans in each child's file. For example, [goals may include] being able to read 80 words, making a story based on pictures, learning multiplication of one-digit numbers, computer skills. (administrator)

Furthermore, an annual progress report, linked to the individualized program of each child, is sent to parents at the end of the school year. The common areas addressed by the report are general development, language arts, mathematics/geometry, geography, biology, history, ceramics, physics, arts and crafts, and music, as well as occupational therapy, massage, and hippotherapy. A simple written paragraph is provided for each subject area to describe the child's accomplishments, areas of need, and suggestions for home planning.

Every year we get a report and learn about his progress. We get recommendations on how to work with our children during the summer. Last summer, I put those recommendations on note cards and placed them everywhere in the house to help us work with our son. (parent)

Individualized planning then translates into differentiated instruction.³ As part of this approach, the content or process of instruction is adapted to allow individual students, with a range of abilities and learning styles, to benefit from it. The level of difficulty is commonly modified in Umut to fit the needs of students (for instance, those who have an intellectual disability). In addition, instruction in Umut occurs through multiple sensory modalities (such as visual, auditory, and olfactory) and, consistent with Waldorf tradition, makes use of experiential learning. Umut teachers are very creative in including all students in the process of learning, as illustrated in the box.

Another component of the Waldorf method that is used in Umut's model is the use of "periods of study" to structure the curriculum. Periods of study are particular topics or subject areas (such as mathematics, the history of ancient civilizations, zoology, astronomy) that students study over an extended period of time (for several weeks or months). A typical day for a seventh-grader in Umut Nadezhda, for example, consists of about two hours of focused instruction (that is, the content of the "period") with about 40 minutes of additional instruction time for foreign

³ Differentiated instruction is defined in special-education literature as a process through which teachers can enhance student learning by adapting their instruction to fit the individual students' readiness, interest, and learning style (Tomlinson, 1999). For example, students who are unable to read and comprehend a long written paragraph may be provided with shorter chunks of the material; students who cannot see well may be provided with larger print; and students who are better at comprehending auditory than printed material may be allowed to listen to audio books rather than read them independently.

language or mathematics. As noted above, periods of study also promote continuity between the subject areas. For example, in the elementary biology lesson using beans, students may practice counting beans, write their names on the cups, and listen to stories about plants.

Perizat, an experienced, energetic teacher at the Center, teaches an astronomy lesson to her group of middle-school students. The topic is the solar system. She first draws various planets of the solar system on a blackboard with colored chalk. She then names each one out loud. Children copy the drawing into their scrapbooks. They look engaged and focused. Kamila, one of the students, assists her female classmate, who is new at the Center. Perizat then uses her own scrapbook drawing and the paper cutout representing the Earth to explain that planets rotate around the sun. She provides verbal instructions in Russian and in Kyrgyz, as a number of students in her classroom have a limited knowledge of Russian. "Let's get in the circle in the middle of the room," she says. "Amir, you will be the sun." Other children are assigned roles of other planets. The "rotation" begins, as children move, independently, on wheelchairs, or with adults' help, around the Amir the "sun," who beams. In the next classroom, transition-age students discuss the physics lesson, where they learned about sound waves and made a model of a telephone out of two matchboxes and a piece of string. They explain that the string needs to be really tight, otherwise "it won't vibrate, and you won't hear anything!" In an elementary classroom, younger children excitedly check the plastic cups filled with potting mix that hold labels with their names—several days ago each of them planted a bean in individual cups, and this morning the first green sprouts appeared in some of them. In simple words, the teacher explains the plant cycle.

Lesson plans are created by each lead teacher using a system of teacher portfolios—unlined scrapbooks that contain teachers' objectives for each of the periods of study, with drawings and illustrations. Portfolios also describe the sub-topics covered within each period of study (for instance, on ancient civilizations, like India, China, and Egypt), ways of introducing the material, and suggested activities. Teachers are encouraged to use creativity in incorporating poems, music, songs, and quotations into their portfolios to make the lessons relevant for themselves and for the students.

Creativity and freedom of expression are also encouraged in students, and progress is measured primarily by meaningful participation rather than the traditional grades and tests.

We do not write in notebooks but in scrapbooks. There are no lines or squares that limit you as in regular school notebooks; it's like a cage. Our ways of thinking are often limited, caged. We all are used to thinking within the boundaries. (teacher)

Some interviewees also highlighted the differences between the approaches and methods used at the Center and traditional models of schooling.

We are very different from regular schools; we let [students] develop their skills. Working here, you sometimes feel like going to regular schools to share how you can work with students. In regular schools, they do rote learning—it's mechanical, and students forget the information soon. Here, children learn through body language, gestures, rhythm, and sensory perception. They will never forget what they have learned. Here, we learn to count by clapping. We learn vowel sounds through body language. For example, for 'O' we open our arms [demonstrates]. When we learn about fruits and vegetables, we let children experience them; we make fruit salads and we learn about forms and colors of fruits. All this will stay with the children. (teacher)

Training and Professional Development

A recurring theme that was discussed by all stakeholders as a unique feature of the Center that makes its approach strong and effective is the use of professional development seminars. The seminars, coordinated by Ms. Schallike, who also conducts many of the sessions, are a critical component of the model that links philosophy, practice, and collaboration. Thus the aspects of program philosophy and specific methods are explained and discussed by the trainees. The seminars also provide specialists with an opportunity to meet and share specific student information and solve problems.

The seminars are mandatory for all teachers and specialists of the Center and are conducted each Saturday between 9 a.m. and 1 p.m. In addition, as noted above, all newly hired specialists have to attend a mandatory intensive training in the summer months and an additional weekly two-hour training for beginners. Additional trainings are conducted during school vacations (four times a year) for staff working in residential settings.

The training model is based on a three-pronged approach involving theory, practice, and creativity. Some sessions are lecture-based, but the

majority are activity-based and include discussions of case studies, brainstorming, and role-playing.

Especially at the beginning of the school year, many of the training sessions take the form of councils dedicated to the discussion of the specific student cases. During those sessions, teachers present student cases and discuss the strengths and needs of each child. Because empathic understanding is a prerequisite for effective teaching in Umut, teachers may be asked to assume the roles of their children in an attempt to better understand their experiences. Teachers may brainstorm ideas related to specific classroom situations and collaboratively plan their intervention efforts. The training provides specialists with an opportunity to share their experiences about specific students' strengths and preferences.

We discuss specific cases, share our vision for each child, discuss ways of helping them. If a teacher has problem with a child, she may not see the cause of the difficulty, but others may share their ideas and perspective, and then we all decide on the plan of action. (teacher)

Sometimes you just see a body, but you need to understand the mind and the soul of children. It's really fascinating. A child may have difficulties in one classroom but flourish in workshops or during music classes, so other specialists may tell us about it. The child's horizons open. (teacher)

Role play—in which one teacher plays the role of a parent and another responds as a teacher—is also used as a tool to help teachers deal with potentially challenging interactions with parents. In addition to targeted discussions of student cases, many introductory training sessions consist of discussions of program philosophy and theory of education and inclusion.

We had heated discussions during our seminar about inclusion; we spent hours and days talking about it. What we did was a role play—one group was assigned the role of people who supported inclusion, and another played opponents. Some people got really passionate—they were yelling, 'Children with disabilities should be included!' and our 'government members' were responding: 'No, there is no money for inclusion. Get in the back of the line' [laughs]. At some point we had to stop and say to ourselves—why are we quarrelling, this is just a simulation. Yet it gets you thinking. (teacher)

Other broad training topics include the importance of understanding the child, a strength-based approach to education, and individualized instruction. In addition, theory and practice related to specific conditions and disability types (such as ADHD, autism, and orthopedic disabilities) are discussed. Importantly, seminar sessions are dedicated to general ap-

proaches to teaching students with special needs (for instance, individualized instruction) and methodology of teaching particular subject areas (including mathematics, foreign language, and physics). Lectures are often followed by discussions and theory-to-practice sessions. Invited speakers conduct some of these sessions. Finally, separate sessions are held to prepare teachers to conduct music, dance, art, and crafts lessons.

Weekly seminars have become part of the Center's culture. Few teachers skip the training, and all appear very motivated to attend. Teachers talked about the seminars as a unique opportunity that they were privileged to have. They viewed the training as the main source of support provided to them in their work.

We are given a free opportunity to increase our professional skills through training... No other organization does that. I have seen many educational centers, but I never saw people do that for free and weekly. I think it is also important for parents to know that every week the professionals working with their children improve their skills. (teacher)

Many trainees view the training not only as a source of knowledge and professional support but also as a tool for self-improvement and intellectual stimulation, as some of the topics discussed include the role of freedom, child development, and philosophy of education. Those general discussions are always tied to specific case illustrations and, as a result, help teachers to understand their students and focus on the long-term goals for them.

Sometimes we look at each other but we do not see. The seminars help us obtain this vision for our children, to see them and understand what we can do, to do no harm but to help them through work on ourselves. (teacher)

Furthermore, some professionals who were trained went off to found their own programs, which are now considered part of the Umut Nadezhda network. Among them are three integrated preschools, located in Ornok village near Issyk-Kul Lake (which during the summer months also functions as a summer camp for children from the Bishkek campus), in Kok-Dzhar village, and in Bishkek. Other former trainees work independently using a similar program philosophy and methodology (such as Obereg Center for students with disabilities in Bishkek). Therefore, the training has been instrumental in dissemination of the Center's approach. As a result, Umut has undoubtedly had an influence on the system of education in the country in general and preschool education in particular. While it is painful for Umut's administration to see some

people leave the Center, they know that many of them are going to remain part of their “family.”

We have enough experience and material here to open a special-education department. There are many specialists who were trained at the Center but then moved on to create their own projects, organizations, and preschools. They use the same approach as us. This means we have spread the word. Of course, it hurts to see a trained specialist leave the Center. At the same time, if everyone were already trained, there would be no need for those seminars anymore [laughs]. (administrator)

The Umut Community

The final area that was extensively discussed by participants in the case study concerned collaboration between stakeholders. Interviewees talked about the sense of community and belonging that they experience at the Center. Weekly training and collaborative work undoubtedly play an important role in building the sense of community shared by stakeholders at Umut Nadezhda. These strong personal and professional relations support them and give them energy.

The sense of community and belonging is also shaped through the system of daily routines (such as the morning circle, described above) and seasonal festivals. It is Umut’s strong belief that all individuals, adults and children, with and without disabilities, need celebrations. As Kyrgyzstan is a multiethnic country, festive traditions of many different cultures are maintained at the Center. One of the most beautiful celebrations is the annual Festival of Lanterns, which takes place in November, when the day gets shorter and it gets dark earlier. For days before the Festival, children and teachers make candles and create paper lanterns. Children, parents, and teachers all walk in the dark outside, carrying their lanterns and singing. The experience is supposed to signify the importance of contribution of an individual to the world: “I can make this world a lighter place for myself and those around me.” This has been life-changing for some.

This is our first year here, and for the first time we participated [in the Festival of Lanterns]—it was then that I realized that children like my son can participate in holidays and be as happy as any other children. You know, society rejects our children, especially in distant villages. People turn away from us, look at our children as if they were contagious. Last year, when I took him out of the institution, we took part in the Festival, and I even cried from happiness. It was our first celebration together. Here we are treated well. When my child is here, I feel confident and calm. I feel that I can do anything. (parent)

It is interesting to note that some stakeholders have multiple roles at the Center. Several parents, for example, also work as specialists at Umut. In addition, many brought their family members, such as younger siblings, to participate in the daily life of the Center and the special activities. Marina, a longtime teacher at Umut and a mother of an adult son with disabilities, explains:

The Center is our second home. All my family members are involved with the Center. My younger daughter attends all the holidays, every season's celebration, the Festival of Lanterns. We come, see our children, and we are happy for them. I know all the first graduates of the Center—they do not want to stay at home, they need to come here and see each other. They are all like a family. We have been together for 20 years. We still keep in touch with each other.

Parents are also invited to monthly parent conferences where their children's progress and daily issues are discussed. Some parents talk to each other and share their experiences.

Sometimes we talk to each other, cry, and feel better. An opportunity to share your story is also a kind of a therapy. (parent)

Many parents volunteer at the Center by helping with repairs, bringing supplies, or doing voluntary work. As one parent of a young child with disabilities, currently a member of the Governing Board of the Center, put it, "we have been with the Center for six years. They help us a lot, so I would like to help as well."

The Teachers

In addition, the overall positive climate is built by teachers and other leaders who work at the Center. Most teachers and parents mentioned the strong leadership and unique personal qualities and dedication of Karla-Maria and Igor Schalike. They were described as "wonderful, rare people. There are few people in the world like them. You have to be so courageous to organize all this, to open the Center like that."

In addition, teachers' dedication, professionalism, and ability to provide highly specialized instruction were described as a unique feature that contributed to the overall positive climate of Umut Nadezhda.

It is already difficult to be a teacher, but it is even more difficult to work with children who have special needs. They require special approaches, love, and patience. I am saying that because even at home we have difficulty with our own child, and teachers have to take care of others' children. So their work is difficult. I am grateful to the administration that there are such wonderful people who work here. (parent)

Teacher interviews also suggest that their work occupies an important place in their lives. To many of them, it is not just a job but a calling.

Everyone is so busy during the day. Sometimes I take a bathroom break and I keep thinking about the kids. I have dreams about them all the time. In one dream I took one of my students out of a cage. Then I woke up and I thought—yes, we will definitely make progress with him. (teacher)

Teachers' personal motivations may vary, but many of the interviewees described the reward of witnessing children's small steps towards success.

First, I was shocked. I did not know that you could work with those children. I stayed because I was curious how to do it. (teacher)

One of my students, Karina, is so active today. She does not speak, but recently, one of the volunteers asked her 'Do you want to play?' and she nodded yes—this was such a big victory. Nobody expected it... After that, you want to work, to see what else they can accomplish, what will happen next. You want to witness their success, you want to live to see them develop. (teacher)

The Students

Teachers shared many additional student stories, describing students' strengths and unique abilities with pride and affection.

Gleb is young, but he is so smart—he is really good at math. [Although] he can only lie down and he does not speak, he can indicate with gestures and eye movements what the correct answer is. You ask him, 'How much is 5 times 5? Is it 30?' and he shuts his eyes to say it's wrong. He loves to communicate, listens to music, loves to dance. We sometimes tease him: when leaving for dance class, we said, 'Gleb, perhaps you don't want to go to dance class today?' and he immediately objected, made sounds [smiles]. (teacher)

While the number of students who transitioned from the Center to the general education settings is not large, several cases were described, most of them students with milder orthopedic disabilities. However, Rita, the preschool teacher, has high hopes for some of her current students.

Finally, a positive peer climate is a strong defining characteristic of Umut Nadezhda. Good peer relations and friendships were observed in the classrooms and other school settings. The interviewees also discussed the importance of social relationships and student collaboration.

They carry each other, help each other, write love notes to each other. One girl asked me to help her write a love letter to a boy. Can you believe it? In the fourth grade! [laughs] It is so unique that all our children understand each other. (teacher)

One of the biggest success stories of Umut Nadezhda Center is the success of the b-boy (“breakdance”) group Tumar. Organized by an enthusiastic young dance instructor, the group has toured the city and, with financial support from Kyrgyzstan’s Ministry of Social Welfare, went to Austria to participate in a local TV talent show. The trip made its participants local celebrities and gained them popularity among their peers without disabilities. The teenagers in Tumar have orthopedic disabilities that prevent them from walking. However, with the help of their instructor, they developed an incredible sense of balance, movement, and arm strength to perform some of the most complex movements of b-boy. The impressive dance moves that we see in their videos, posted on the Internet, are only the tip of the iceberg. Behind them lies difficult daily work by adolescents and their teachers who train them and give them confidence. Although some of the Tumar participants were initially shy and self-conscious, they now feel comfortable in front of the big audiences. They are independent and have made friends in their local community. They are also vocal in promoting society’s awareness of disability. One of the video clips featuring the group ends with the caption, “Can you call us *persons with limited abilities*?” The next challenge that the youngsters face is completing high school and finding productive employment.

Current Challenges

The major challenges and barriers described in stakeholders’ interviews fell into several main groups: (a) interaction with government and the formal education system, (b) accessibility of environments and services, (c) societal attitudes, (d) teacher turnover, and (e) difficult life situations.

First, interactions between the Center and the system of formal education have been, at times, difficult. The law guarantees education, yet many students with disabilities still do not receive any education.

All the laws are in place—in fact, there is no need to change them. The laws in our country are excellent, but in reality, they are not always implemented. Everyone says ‘yes, we want inclusion,’ but the reality is different. There are no trained specialists, no money. We will keep trying nonetheless. (administrator)

Unfortunately, although the legislation has been updated to include the appropriate rhetoric with regard to education and the inclusion of students

with special needs, it is more difficult to get rid of the old ways of doing things.

Some children with disabilities are still considered ‘unteachable’ and are not accepted into regular schools, even if we try. Even children with average intelligence and some motor difficulties have a hard time getting in [general education] schools—nobody wants them, only some private schools may accept them. (administrator)

Because of the stigma attached to having a child with disability and significant emotional stress, fathers of children with disabilities frequently leave families, and mothers raise their children alone. A lack of financial support, coupled with bureaucratic practices, creates additional difficulties for families already struggling with the emotional stress of having a child with a disability.

Society does not even take care of the basic needs of our children—my child’s monthly pension was withheld for two months. You see, I am registered in a village, so when I came to get my son’s pension in Bishkek, they said it was too late. Only after a fight did I get the money they owed us. (mother)

A lack of accessibility of services and environments is another big challenge faced by many families. Many students with disabilities are home-schooled and never leave their houses. This may happen, in part, because of a lack of services.

I suggested [to the authorities] let’s not give the label ‘unteachable’ but instead say ‘we have failed to create educational opportunities for those children.’ This is a fact. It is not the child’s fault; it is our fault. (administrator)

Another barrier is a lack of information about relevant services, particularly among families from distant villages.

There are many children in our country who have a disability and never leave their houses. There are perhaps about 5 percent who attend centers. There are many people who want their children to attend our Center, but we just do not have the capacity anymore, as the state does not help us; we do not have the resources. On the other hand, some parents do not even know about the Center. One of our students stayed at home for 12 months before getting to us. (teacher)

Yet others simply cannot leave their apartments or houses because of a lack of transportation, accessibility, and difficulty in providing for health needs of their children.

We live in an apartment, and the building is not accessible; nothing is accessible—shops, streets. We cannot even take [our boy] to the hospital, because you cannot take a wheelchair there. (parent)

Teachers who work at the Center face similar difficulties in their work.

You always have to think about accessibility. Now it is holiday season, and we are invited to many New Year parties, so we have to think where we can or cannot go, whether some children may go by public transport, whether the buildings have wheelchair access. (teacher)

Third, even when Umut students do get out for a community trip, societal attitudes toward disability create invisible barriers to their inclusion.

When we first started the Center, the neighbors shut the doors and built gates around their houses, as they were afraid. They wanted us to move away. Every night we were harassed. There were noises. One morning we discovered that all the pigeons in our pigeon house were killed overnight. What we did was go around the houses and talk to the neighbors. We said that we work here, we are ordinary people, and some people are trying to intimidate us. Then we found out that members of the community committee went from door to door as well and talked to people, and so did a local police officer. After that it stopped. Now, attitudes have changed a lot. The neighbors accept us. (administrator)

Although in recent years some community members have become used to seeing individuals with disabilities in parks and cafes, many still react with shock, pity, or disgust.

We sometimes take our students out to the community, and I feel embarrassed for how some people react. Those gazes, comments, staring. Students who understand it are really hurt. They prefer not to go outside. A few students though, like our Anna, have an amazingly strong ‘immune system’—they don’t give a damn about others’ opinions. (teacher)

The negative attitude of community members to individuals with disabilities still results in the abandonment of some children to state care.

In our society, children with disabilities are viewed as ‘second-class’ children who should live in institutions. Some of my family still think so. At some point, I did place him in an institution—you should see what condition he came back in, thin and scary. Now he has gained weight, but before then, the specialists were afraid to touch him. (parent)

Labeling and stigmatization are issues that administrators and teachers are truly concerned about and hope to change.

A journalist once approached me, and I told him I did not like the label ‘people with limited abilities.’ I asked him, ‘Can anyone boast unlimited abilities?’ He laughed and thought it was a joke, but it was not. I was very serious. (administrator)

Finally, teacher turnover is a big practical barrier faced by Umut Nadezhda. First, the training model attracts many recent college graduates who get experience and professional development and soon leave the Center to work in international non-profit organizations or emigrate to neighboring countries where the pay is higher. Second, dealing with challenging behaviors such as aggression and self-injury is an emotional strain, which may lead to burnout that not all specialists can handle. Nonetheless, a number of teachers have been with the Center for more than 10 years.

Hopes and Vision for the Future

All stakeholders were asked about their hopes, concerns, and dreams about the future for the students. A recurring theme was the need for secure employment and independence.

One mother shared:

He is over 20 now, and he tells me: I cannot depend on you all my life. I must earn some money, I want to bring something to the family. He does not feel comfortable that he does not bring any income except his pension. He thinks about it a lot, and I am worried that he may even get depressed. He has a younger sister, and he tells me: I want to be able to give her a birthday gift [bought] with my own money.

The same hopes for a productive independent life and employment were shared by young people with disabilities and by their teachers.

My mom hopes to find me a job. So far it’s just here [the workshops]. It’s good here. I want to be a photographer. We have a friend who is a photographer, and I want to do it too. I want to take pictures of everything. The main thing is that they pay me money for that. (student)

We want them to be helped by the government. We want them to get to college, to get a job; we want more teachers for them, we want them to have self-help skills. There should be more organizations for adults with disabilities. We want them to flourish and live a productive life, to be needed by society. (teacher)

Personal hopes and dreams were also related to health and well-being.

I haven’t decided yet what I want to become. Everyone asks me, and I am still not sure. I’m changing my mind a lot. Sometimes I get scared. In the future, I would like to be able to walk... I do not like to have family. When I grow up, we will see. My main dream is to be able to walk, and time will show what’s next. (middle-school student)

Finally, hopes and dreams were discussed in relation to the system-wide changes that need to happen in order to improve the quality of life and education for individuals with disabilities. Most individuals spoke of the personal responsibility they felt for changing the situation for the better.

We need to begin doing something so that the situation for all children improves. As a parent, you cannot just try to improve the life of just your own child—you cannot shield your child from the overall situation, from society. They need to adapt, to interact with their environment. We ourselves need to promote inclusion. We will not be around forever, so we need to improve the situation right now. (parent)

The Schalikes believe that the educational reform that would result in improved opportunities for children with disabilities should originate in preschools. “We should use the existing resources wisely. We cannot just say, ‘Starting today, we will have inclusive education everywhere.’ There is a lack of money, a lack of trained specialists, and parents are not prepared. We therefore propose to make inclusion a 10-year plan,” says Karla-Maria Schalike. In her opinion, inclusion should begin with the professional training of just a handful of preschool teachers. This initiative needs to be supported by the government and should not cost much. The trainees would be provided with a one-year intensive course on the education and inclusion of children with disabilities in preschool settings. Once they began working with young children, they would show success; success stories would be shared through word of mouth and media releases and Internet publications with other specialists, parents, and a larger community. Eventually, more and more people would get on board, and additional preschool and elementary teachers would be trained. “It will be like a snowball,” Ms. Schalike states. As young children with and without disabilities grow up together, they will form friendships and peer groups and move on to elementary schools together, as a cohort. In addition, parents will embrace the idea of inclusion, while teachers will become more competent and prepared. “So our hope is that in about 10 years there will be inclusion in Kyrgyz schools.”

Some interviewees also shared their vision and hopes for possible changes in social attitudes.

I think people’s knowledge and exposure should change; it should start from a very young age, has to happen gradually. I have a young son who hangs out here [in the

school] all the time, he knows our students and does not see their differences. My older daughter, on the other hand, is wary of them. So it has to start really early in life. It has to be accompanied with appropriate information. (teacher)

Lessons Learned and Conclusions

Several conclusions may be drawn from the case study described above, which may serve as lessons for other individuals and organizations working with students with disabilities in the region and in other parts of the world. Those lessons are related to the unique or promising features of Umut Nadezhda's approach described by stakeholders and observed during the visits to the Center.

The importance of inclusion, acceptance, understanding, and respect for individual differences, and the primary focus on strengths rather than difficulties, are all emphasized through weekly training, everyday work with students, and the Center's collaborative culture. Many aspects of Umut's theoretical framework are derived from the humanistic principles of Waldorf education; however, those are mainly universal assumptions that are nonetheless important to emphasize when working with students with disabilities.

The approach to education used in Umut Nadezhda is child-centered, and services and interventions are planned to fit the needs of individual students. Furthermore, the approach is comprehensive, involving children of different ages, ability levels, and individual characteristics. Finally, an integration of different services (such as physical rehabilitation, behavioral planning, and academic interventions) is another component of the comprehensive Umut model. Collaboration of different professionals in assisting children in various aspects of development is particularly important when working with students with severe and multiple disabilities, who may have the greatest needs.

The way children are grouped at Umut deserves further mention. While it may be more convenient for special schools and rehabilitative centers to group students by disability type (an arrangement that has traditionally been used in Kyrgyzstan), placing children with mixed abilities and diagnoses together may be beneficial. First, students may benefit by getting exposure to positive role models. Second, teachers in mixed-ability classrooms may be more likely to differentiate their instruction instead of focusing on a rigidly prescribed set of methods. Although there are currently no fully inclusive classrooms at Umut, the same arguments

may be used to advocate for the use of inclusion. On the other hand, differentiation may be challenging to implement without extensive teacher training and experience, so some students may not realize their potential to the fullest if inclusion is not well-supported.

Another crucial feature of Umut's approach is the relatively high staff-to-student ratio. Adequate staffing is important, as it increases the likelihood of individualization. Furthermore, children with multiple and motor disabilities, such as some students at the Center, may need one-on-one assistance in performing the physical requirements of classroom activities. Umut has demonstrated creative ways of improving the classroom ratios without greatly increasing costs—for instance, through inter-agency collaboration. Umut's links with local universities have allowed them to organize internships or student teaching experiences. Interns and student teachers are invaluable staff members who also benefit from their classroom experiences and in-service training offered to them free of charge. Another unique feature of Umut is collaboration with volunteers from Western Europe. This is mainly accomplished through the program director's personal connections but may be possible in other cases as well. The downside of the use of student teachers and volunteers is that their presence is temporary; their departure may be hard on students who get used and attached to them (although in some cases, student teachers and interns have stayed on at the Center as full-time employees).

Arguably, the most important component of Umut's model is its effective use of professional training. "Theory, practice, and creativity" are the three pillars of the training, which is mandatory for all specialists of the Center and may be attended by members of other organizations and by Umut parents. The training curriculum covers the theoretical underpinnings and practice of working with students with disabilities, the importance of inclusion and individualized approaches, and involves collaborative discussions of specific practical cases. Training is part of the Center's culture; it is viewed as a valuable learning opportunity available for teachers, an opportunity that may be empowering. Thanks to the training, the Center has become a magnet attracting a large number of specialists not only from Umut but also from related organizations, including trainees from geographically distant areas. As stated earlier, it is the training that made possible the dissemination of Umut's model, as numerous organizations' staffs have been trained and are currently using the same framework in their independent work.

As with many other aspects of Umut's work, strong leadership, personality, and the active investment of the Center's administration may

contribute to its overall effectiveness. Thus the role of the administration is to coordinate, supervise, and conduct training; to provide connections with community organizations, universities, government, and mass media; and to engage in outreach to private donors and organizations for fund-raising.

The Center is viewed as home by many individuals, including students, teachers and other specialists, graduates, and parents. Teachers collaborate via the system of training that offers them an opportunity to discuss specific issues and cases. An interesting aspect of Umut's model, which may be replicated elsewhere, is the use of parents as specialists and/or volunteers. Parents are also encouraged to come to the Center and to attend the training and are invited to monthly parent conferences, which is important in empowering parents, providing them with information and emotional support.

The focus on self-governance in the organization's administrative structure is a recent feature of the Center. As part of the self-governed administrative model, lead teachers also serve as administrators of their programs, which may be as small as individual classrooms. This approach has the advantage of being flexible and cost-effective. However, this model also creates additional teacher responsibilities, as lead teachers are held responsible for every aspect of their program's functioning, including purchasing the materials and food, taking care of children's basic needs, delivering instruction, and communicating with parents.

In terms of specific methods and approaches to education, individualized planning and differentiated instruction are widely implemented at the Center (even though the terms are never used). First, all students have individual programs that include their learning and developmental goals. The programs are also used as a way to communicate with parents, with progress reports sent to them on a regular basis. Second, students with the most significant disabilities are never excluded from participation in subject lessons such as biology and physics; the material is adapted to make their participation meaningful. Third, the use of multiple modalities of instruction, inherited from Waldorf education, is another way of providing differentiation. By presenting the information in a variety of modes, teachers are more likely to reach out to students with diverse learning styles and needs. Another feature of Waldorf education, which is consistent with the current best practice and is used at the Center, is the use of rhythms. The system of rhythms brings structure and predictability into daily and weekly routines of students at Umut. This may be crucial for students with severe disabilities, helping them navigate and master their

environment. Finally, the promotion of teacher creativity, encouraged in Waldorf's education, may result in greater use of hands-on activities, project work, arts and crafts, storytelling, and diversity in instruction, thereby accommodating a greater variety of student needs. These aspects of teaching are relatively easy to implement in the context of a school that values teacher autonomy and creativity.

Conclusion

For over 20 years, Umut Nadezhda Center has been at the forefront of providing educational and rehabilitative services to children with severe and/or multiple disabilities in the region. The work of the administrators and teachers of the Center, often conducted against the odds of poverty and exclusionary practices still prevalent in the society, has contributed and will undoubtedly continue to contribute to the positive changes in the region. Big changes are accomplished through small steps—the careful, hard work done every day by the specialists of the Center.

“Our experience shows how one can accomplish one's goals. The process may be slow, but those goals are achievable and real. The thing to remember is not to try grabbing the stars from the sky... you can fall and hurt yourself if you do so... [laughs], but you can try to gradually, slowly reach for them. I don't know... perhaps we will succeed.” (administrator)

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Conclusion: The Road Ahead

Kate Lapham and Martyn Rouse

“The children are not guilty; they live in our society. They do not need to be isolated. This tolerant relationship did not develop in one day, but over years. Now this work continues.”

Principal, School 13, Petropavlovsk, Kazakhstan

The path to inclusion for children with disabilities and other special-education needs is long and complex. It has been claimed that inclusion is not a destination but a process of increasing participation and reducing exclusion from the culture, curriculum, and community of mainstream schools (Booth and Ainscow 2002). Setting out upon this journey to inclusion is acknowledged as a necessity in Central Asia if all children are to participate in education, but it raises many questions and quandaries. It also stirs the ghosts of social norms and traditions from the past that differ from place to place, even within the former Soviet Union. Central Asia presents particular challenges because of the economic, social, political, and educational upheaval and disruption that has affected the region in the past two decades.

Every country's path to inclusion and inclusive education will be different. There is no single road map. Instead the journey should be informed by the principles of equality, equity, and human rights, together with a common vision of classrooms and schools that promote learning and participation for all children that are supportive of the types of societies and communities we want to build. Developing a shared understanding of such a common vision is just one of the challenges to be faced. In Central Asia, as in many other places, there are multiple visions of how best to develop inclusive education and reduce exclusion.

It is tempting, especially for advocates, to use research on marginalization and children with disabilities to gather evidence about ways that society discriminates through stigmatizing children, through the segregated provision of services, or through discriminatory regulatory frameworks.

This evidence is important for demonstrating inequalities and for stimulating discussions about change, but the pictures painted by such research are often static and focus on barriers rather than achievements. Progress to inclusion may be slow, but in this part of the world it is often not acknowledged or known about locally, or more widely. Thus it is important to document and share ongoing work and innovations that mark progress toward greater inclusion, in all their complexity and messiness. As part of this process, we must also advocate more supportive government policies and more positive social norms to provide a context that will encourage the journey to greater inclusion and not fall into the trap of constant negativity.

In reviewing the current policy context, it was suggested in the introduction to this book that questions should be asked about the extent to which education policies and practices include or further marginalize the most vulnerable. Other questions are important. How are services structured to account for the needs of different groups? Are government programs using education as an equalizing force, particularly in the early years? Does the broader community of teachers, parents, and children have meaningful opportunities to participate in the conception, design, delivery, and monitoring of schools and schooling? By asking these questions we can think about whether policies are inclusive in their design and implementation. In turn, by observing inclusion at the community, school, and classroom levels, we can see the realities of how policy supports practice and think about the next steps along the road. Even in the least supportive policy contexts, there are spaces in which tentative steps to inclusion can be taken.

The six cases collected here provide an overview of the complex, messy, and sometimes imperfect innovations as they exist now alongside aspirations for the future. They document both the progress and the barriers to improving educational provision and participation for children with disabilities. They describe and analyze changes to an understanding of disability advocacy and inclusive education in Central Asia. The stories have echoes of past developments in many Western countries, but they are specific to Central Asia because of the education systems, cultures, and histories of the region. There are detours and bumps on the road to inclusion that are associated with attitudes to disability and the Soviet legacy of categorizing disability, the segregation of some children into special institutions, and professional approaches based on the concept of defectology. In addition, the region's economic, social, and cultural histories and traditions have to be taken into account. While many of these circumstances

may not be conducive to the development of inclusive, participatory educational innovations, the first steps on the road to inclusion have been taken, and some interesting lessons are emerging.

These cases are not meant to contribute to new ideas about inclusive classroom practice or methodological scholarship on inclusion. Instead, they contribute to scholarship on a series of under-researched themes in Central Asia and on the many paths taken towards greater inclusion through the nexus of programs, policy, and advocacy. Although some of the challenges are specific to the region, many of these themes have parallels in other parts of the world.

- Overcoming the shame and stigma associated with disability and the importance of parents in challenging existing norms and expectations about disability and the purpose and nature of schooling
- The role of civic society associations, advocacy groups and non-governmental organizations (NGOs) and the importance of “seed money” to get things started
- The emergence of new ways of working with government agencies
- The role of professionals as innovators (and resisters) and the need for sustained, high-quality professional development to support flexible educational structures and approaches, especially to pedagogy, assessment, and the curriculum
- The need for new forms of professional preparation of teachers and other professionals to reflect the changes in schools and new approaches to disability
- The need to develop the research capacity and presentational skills of practitioners and advocates so that innovative practices can be documented and shared with a wider audience.

The important role played by parents in bringing about change is apparent in several of the case studies. Many of the struggles that families face in ensuring that their children receive education are common across countries and cultures. As in other parts of the world, parents have been instrumental in advocating, not only for their own children, but also for others, though the formation of parental support and advocacy groups linked to particular disability groups and to inclusion more broadly. Just as parent advocates were responsible for pushing inclusive education forward child-by-child in the West (Booth and Swann 1987), parents are central to the journey to inclusion in Central Asia.

The role of civil society, advocacy groups, and non-governmental organizations (NGOs) has been crucial in many of these cases. Because

there is not the same history of civil society and advocacy in the former Soviet Union, many of the associations that are at the heart of these case studies are in their infancy. However, they represent powerful examples of what can be achieved when people come together to work for specific causes. It is apparent that the success of such groups (for example, Ashyk Alem) is, in part, dependent on high levels of social capital within the membership. Nevertheless, there are other examples, which demonstrate the power of persistence by individuals in hostile circumstances. The role of NGOs in supporting these efforts is crucial. Parents and civil society are leading the conversation about inclusion. The cases illustrate the importance of making allies within the government agencies and the bravery of individual people in challenging stereotypes quietly, every day.

Several cases in this volume provide accounts of the details of the mutual support between parents to take these first steps in advocacy. In some cases they came together informally or as a result of services or education programs offered by other agencies. The founders of Ashyk Alem, an association of parents of children with autism, met during parent-education classes provided by the Center for Social Adaptation and Professional Rehabilitation in Almaty, Kazakhstan. The Association of Parents of Disabled Children (APDC) in Tajikistan started as a single initiative group housed in the Psychological-Medical-Pedagogical Commission in Dushanbe, where parents seek referrals to health and education services for children with disabilities. In both cases, their relationships with the state agencies that helped create them are friendly, but the scope of their activities has grown well beyond the initial vision of the professionals who saw a need for mutual support among parents.

Establishing and maintaining such organizations costs money, and this is a challenge in societies where money for registration fees, office space, and other costs is scarce. The importance of seed money from the international community is vital in helping with the startup costs of such organizations, but local funding must also be found to ensure long-term sustainability.

Many of the organizations featured in the case studies have mounted media and other public campaigns to raise awareness of disability and to challenge existing assumptions and stereotypes. In Central Asia, for many families, the first challenge is overcoming the widespread cultural stigma associated with disability as a divine punishment or sign of family dishonor. While family stigma surrounding disability exists in other cultures (Edwardraj 2010; Werner 2012), it is particularly severe in Central Asia. Thus many families need support to bring their children with disabilities into the community rather than hiding them at home.

Maybe five percent of children with disabilities study in school, because in the villages they are ashamed. They think that if they see my child, no one will marry my daughter. I would tell them, "Look, I have a disabled child. Look, my child reads. You won't always be alive. The child will need to work... If he can read, he should, so that when he gets older he can do some work. He can get married. If he stays at home, all of his abilities will go away." The problem is the parents. The children are always agreeable. They want to be together with healthy children, but the parents are ashamed.

—from Gatling and Juraeva case

Thus it is important that the parent organizations that feature in some of the case studies began as mutual support groups and later began to provide services for parents and children, including legal counseling, occupational therapy, and daycare. They have since grown beyond support and service provision alone to become movements raising public awareness and advocating for the rights of children with disabilities. Ashyk Alem is now working to unite parent groups across the region through the Central Asia Autism Network. The APDC has become an independent network of 11 associations and nine new initiative groups across Tajikistan. They rally around families denied access to services or community participation as a result of disability.

Since parents of children without disabilities are sometimes fearful of inclusive education, worrying that their children will receive less attention from the teacher, parents and professionals who can speak from experience about inclusion are vital to the transition to more inclusive schools. It is important to explain that successful approaches to inclusion can benefit all members of the school community. Nevertheless, there are immediate and valid questions that school principals and teachers ask about implementing inclusive education policies. Existing policies on assessment, pedagogy, and curriculum are inflexible, and school buildings across the region are inaccessible to children (and adults) with impaired mobility and other disabilities.

While the physical infrastructure of buildings can be adapted at a relatively low cost and the school day can be reorganized, implementing these or other solutions requires that education ministries and local education departments empower school administrators with sufficient flexibility to define their schools' needs. In addition, professional development for teachers, together with support and information for parents, is required. Access to sufficient public funds to support these changes is vital.

Beyond infrastructure and the framework of the school day, other challenges to inclusion arise from slow progress in understanding disability, traditional didactic approaches to pedagogy, and conflicting educational

policies, which emphasize elitism. The legacy of defectology presents particular barriers, particularly in its approaches to assessment and categorization and the ways in which some professionals have been trained in this tradition and believe that they have a monopoly of skills and knowledge about disability. The case studies clearly demonstrate the ways in which some professionals misinform parents and attempt to block inclusion. Lack of professional development opportunities for those who trained in the past and who still cling to traditional ways of working can make the road to inclusion rocky.

Thus the importance of high-quality, sustained professional development for all those who work with children and new approaches to teacher training is vital. It is possible to use lack of training as an excuse for not trying to make schools more inclusive. However, in all of these cases, we see individual teachers, progressive defectologists, and school principals who have taken risks in developing inclusion. Their firsthand experiences are essential guides on the road to inclusion. As a teacher in Kazakhstan said about her first student with autism,

It was very difficult for other teachers to believe that these children can be taught together with regular students. I didn't believe it myself at first. But when I started getting the results from Kasym, I realized that it was possible and that this boy could learn like everyone else.

—from Markova and Sultanalieva case

Indeed, innovation by individual educators, in advance of widespread acceptance of inclusive education or in spite of a less-than-supportive policy environment, emerges as a central theme of this volume. Without their brave first steps, others would be reluctant to try including children with disabilities in their classrooms, schools, and communities. Equally important, these cases argue for the importance of flexible education standards and professional learning communities within schools. For inclusive education to be successful, especially in the face of steep learning curves and severely constrained resources of Central Asian education systems, it is vital that schools work in a spirit of collaboration and support that demonstrates the same respect for teachers as for the children in their class. Teachers must be empowered as professionals through trust and professional development to differentiate instruction in their classrooms and to work with parents and children to set individual goals for progress. The discussion club for teachers at Petropavlovsk School 13 and the weekly meetings and intense training sessions at Umut Nadezhda are both exam-

ples of this type of mutual professional support and mentoring among teachers in practice. Nevertheless, coherent national policies on professional development for inclusion and the reform of initial teacher education in the state pedagogical universities are essential if teachers are to be better prepared to work in inclusive ways in the medium and long term (Rouse 2010; Florian 2011).

Many reviews of educational participation in the region (UNICEF 2007, 2010, 2012; OECD 2009) and internationally (UNESCO 2010) have encouraged the expansion of successful innovative programs for children with special educational needs as the means for achieving education for all. Such recommendations are valid, but there is still much work to do. These cases provide evidence of local models of attempts to develop inclusive education. Some of the pedagogical practices and services in these cases do not match current Western expectations for inclusive education. Clearly, there are ways that services, like the professional development for teachers offered by Umut Nadezheda in the case presented by Kokina and Bagdasarova, could be better integrated in the formal education system. These are first steps on the path to inclusion, and they are not perfect, nor are they fully developed. However, they contain lessons for policymakers and professionals that could usefully be incorporated into the broader discussion of education reform and into attempts to ensure that all children are educated.

As mentioned in the introduction, education systems and state agencies are not monolithic. There are spaces for innovative practice to develop, even when the policy context does not seem supportive. In Tajikistan and Kyrgyzstan, state agencies responsible for education and social protection are not always able to deliver the types of services that would fulfill their mandates. NGOs have filled some of these gaps by providing necessary and sometimes innovative services, often with funding from international donors and INGOs. Government agencies' responses range from gratitude to outright distrust and feelings of competition.

However, the models of service provision developed within these NGOs seldom become part of the state system, even when funding for substantial reforms is available through direct budget assistance. In Kazakhstan, the SATR (Social Adaptation and Professional Rehabilitation) Center, the NGO that was the catalyst for the founding of Ashyk Alem, was originally created to seek grant funding and try innovative programs that the National Research Center for Correctional Education in Almaty (NRCCE) could not access because of the regulations governing state agencies. SATR still exists as a service provider and innovator in inclu-

sive education in Kazakhstan. In turn, it has nurtured a parent movement that is a much more recognizable form of civil-society engagement. If inclusion is truly a policy priority, it is vital that governments look beyond institutional inertia to take advantage of the opportunities afforded by natural resource wealth and international assistance mechanisms to incorporate and build upon locally generated models of inclusion.

From these cases, we can see that inclusive education is not necessarily embraced by education systems in Central Asia, but it has moved more centrally to discussions of education reform through policy advocacy, innovation at the grassroots level, and increased public awareness to generate the political will for change. Its cause is taken up and advanced by individual agencies with progressive leadership or individuals willing to assume the risk of innovation. The sharp contrast in orientation between the Almaty City PMPC and the national PMPCs in Kazakhstan is a clear example of the uneven trajectory for policy implementation. The support of the Dushanbe PMPC for the nascent parent movement in Tajikistan described by Whitsel and Kodirov is another. If inclusion is to advance in the region, it will be important for advocates to recognize their natural partners within government agencies so that together they can insure that inclusion remains a part of public-policy discussions and social-service delivery.

Finally, the cases in this volume demonstrate that one type of inclusion often leads to another. Schools that started by accepting children with physical impairments expanded their definition of inclusive education to work with children with sensory and intellectual disabilities. Their concept of who can attend a regular school expands with each step toward greater inclusion until we leave behind the notion that there are children who cannot be taught or who should be segregated from their peers.

Furthermore, the development of teaching methods for inclusion of children with disabilities may also support the inclusion of other children and help communities cope with social and demographic change. Aichileva and Hartblay tell the story of an international project supporting the inclusion of children with disabilities; the teaching methods and philosophy it used helped teachers to cope with huge demographic shifts, as families from Belovodsk migrated out of the region in search of jobs and were replaced by families from poorer areas of southern Kyrgyzstan.

The case studies were carried out using an innovative, collaborative approach to their design, construction, and writing. The introduction to this book describes how the local researchers, who had deep knowledge of the specific cases, were supported by external researchers, who had skills

in conducting qualitative research and the local language skills. The intention of the case studies was not to conduct program evaluations but rather to produce a series of illustrative case studies that would convey candid accounts of the richness, complexity, and messy nature of such development work, while also being as methodologically robust as possible. The cases presented in this volume are the result of this process, and we hope that they will prove helpful to others with an interest in studying and furthering this important work.

As the countries of Central Asia continue on the road to inclusion, we hope that these cases will provide signposts and helpful insights. They highlight the commitment of many individuals to inclusive education through activism and practice. The growth of parent movements and the signing of the UN Convention on the Rights of Persons with Disabilities (United Nations 2006) in Kazakhstan and Kyrgyzstan are indicators of growing acceptance and support for inclusion at the grassroots and the policy levels. Beyond documenting this trajectory for scholars of the region, we hope that these case studies will provide an impetus for further progress through the incorporation and development of local models of inclusive education into common practice. We also hope that policymakers will continue to create opportunities to consult educators, parents, and people with disabilities when developing educational innovations. If education for all is to become a reality in the countries of Central Asia, then inclusion is a necessary precondition. Such a radical reconceptualization of the nature and purpose of schooling will take time and will need support, but as the director of School 13 in Petropavlovsk, Kazakhstan, reminds us, "This tolerant relationship did not develop in one day, but over years. Now this work continues."

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The path to inclusion for children with disabilities and other special education needs is long and complex. It has been claimed that inclusion is not a destination, but a process of increasing participation and reducing exclusion from the culture, curriculum and community of mainstream schools. This volume chronicles the journey toward greater inclusion of children with disabilities in Central Asia. Setting out upon this journey is an acknowledged policy goal in Kazakhstan, Kyrgyzstan, and Tajikistan so that all children are to participate in education, but it raises many questions and quandaries. It stirs the ghosts of social norms and traditions from the past that differ from place to place, even within the former Soviet Union. Central Asia presents particular challenges because of the economic, social, political and educational upheaval and disruption that has affected the region in the past two decades. These six case studies document the progress and challenges along the way through the stories of specific children, families, schools, and organizations across the region with the goal of keeping inclusion on policy agendas and in public discourses. It is a resource for scholars of the region, education researchers, and practitioners alike.

"Before I thought that children with disabilities had to be separated. Now I believe that we are all equal. Children with disabilities have the same rights and should be together with others. We are all different. We are all people. One needs to find strengths in any child. Our goal is to educate all children, but individual characteristics and ways are different."
(teacher from the Umut Nadezhda Center in Kyrgyzstan)

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